DEPARTMENT OF COMMUNICATION SCIENCES AND DISORDERS
FACULTY OF HEALTH SCIENCES
UNIVERSITY OF CAPE TOWN

Faculty of Health Sciences
University of Cape Town

# Implementing a group intervention programme emphasising early communication stimulation with parents of children with Autism Spectrum Disorder

**By: Aneesa Osman-Kagee (OSMANE002)**

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**Supervisor: Dr. Michal Harty**

Department of Communication Sciences

and Disorders

Faculty of Health Sciences

University of Cape Town

# Declaration

I, Aneesa Osman-Kagee, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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**Date**:10 February 2020

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# ABSTRACT


**Implementing a group intervention programme emphasising early communication stimulation with parents of children with**

**Autism Spectrum Disorder**

**Introduction**: Implementing low-intensity interventions, such as group-based parent education and training (PET), is a cost and time effective way of providing early intervention for families and their children with autism spectrum disorder (ASD) in low- and middle-income countries (LMICs). Relatively little empirical research demonstrates the effectiveness of parent education and training in this context.

**Methods**: The study aimed to develop and pilot a group-based parent education and training (PET) programme (COMPAS) and determine its appropriateness and acceptability. Secondly, it aimed to investigate the clinical effectiveness of the programme to improve the communication interaction skills and self-efficacy beliefs of parents of young children with autism. The study followed an exploratory sequential mixed methods research design and used the Replicating Effective Programs (REP) framework. Sixty-one participants took part in the study which consisted of 3 phases. In phase one we developed the programme and teaching materials and activities. In the pre-implementation phase, we collected qualitative and quantitative data via questionnaires from two stakeholder groups (25 parents and 5 autism experts). In the implementation phase, we used a single group pre-test post-test design with 31 parents of children with autism to determine changes in parent-child interaction and parenting self-efficacy. The primary outcome of the implementation phase, parent-child interaction, was measured using the Parenting Interactions with Children: Checklist of Observations Linked to Outcomes (PICCOLO), and the secondary outcome, parenting self-efficacy, was measured using the Parenting Sense of Competence Scale (PSOC) and the Parenting Self-Efficacy Measuring Instrument (P-SEMI).

**Results**: In the pre-implementation phase, a panel of experts agreed the training content was comprehensive and relevant, and that the manual was user-friendly. After the pilot study parents felt confident that they could use at least one of the strategies taught during everyday routines or play with their child. Results from the implementation phase indicated significant

improvement in parenting interactions ($p < .05$, $d = 1.26$) and self-efficacy ($p < .05$, $d = 0.35$) after the training.

**Conclusion**: We developed and piloted a training programme in a LMIC setting which resulted in increased interaction skills and self-efficacy for parents of young children with autism. This study indicates that brief, group parent education and training in a LMIC is feasible and can be effective in improving parenting skills and feelings of competence.

**Keywords**: Autism Spectrum Disorder; low and middle-income countries, parent-child interaction, parent education and training; parenting self-efficacy.

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# Chapter: 1

# Orientation and Introduction

## 1.1. Introduction

This chapter provides an overview of the reasons for conducting the current research and includes an outline of the content of each chapter, as well as a list of the terminology and common abbreviations used throughout this dissertation.

## 1.2. Statement of the Problem

Autism Spectrum Disorders (ASD) is one of the most common neurodevelopmental disorders globally (Franz et al., 2018). Autism is a lifelong developmental disorder that is characterised by impairments in the areas of social interaction, communication, restricted and repetitive patterns of thinking and behaviour, as well as impairments in sensory processing (American Psychiatric Association, 2013). While the effects of ASD and the severity of symptoms are different in each person, notably between 50-71% of these children do not speak and over 60% have reduced intellectual functioning along with other associated difficulties (Abubakar, Ssewanyana, & Newton, 2016; Baio, 2018). Many children with autism have great difficulty initiating social interaction and responding to verbal and non-verbal communication.

There is consensus amongst professionals that the worldwide prevalence of ASD is around 1% (De Vries, 2016) . The Centers for Disease Control and Prevention (2018) estimates that 1 in every 59 children has been identified with ASD (Baio, 2018). As a consequence, global concern regarding the prevalence of ASD and awareness of the associated burden of the disease has increased significantly over the past decade (De Vries, 2016; Guler, de Vries, Seris, Shabalala, & Franz, 2018). Due to an absence of rigorous population-based prevalence studies the rate of autism in Africa is still unknown, however local researchers are inclined to believe that rates of autism in Sub Saharan Africa (SSA) and Africa are not any less than elsewhere in the world (Abubakar, Ssewanyana, de Vries, & Newton, 2016; Chambers, de Vries, Delehanty, & Wetherby, 2018; Franz et al., 2018). In recent years great developments have been made in the identification and treatment of autism spectrum disorders (ASD) and related neurodevelopmental disabilities on a global platform (Black et al., 2019, 2017; Olusanya et al., 2018). However, the majority of what we know about ASD comes from resource rich countries,

such as the USA, UK and European countries, notwithstanding that 90% of people who live with ASD, live in LMICs, such as Africa (De Vries, 2016). Sub Saharan Africa (SSA) is home to more than 1 billion people, which equates to 15% of the global population (De Vries, 2016). Yet, recent published findings from Africa are scarce, resulting in very little knowledge about ASD and neurodevelopment in this setting. More specifically, there is a dearth of empirical evidence from LMICs that directly addresses the effectiveness of parent education and training (PET) programmes on parents of young children with autism. (De Vries, 2016). Given the low baselines of knowledge in low and middle-income countries, including South Africa, a pronounced research-to-practice gap exists (Chambers, de Vries, Delehanty, & Wetherby, 2018; Franz et al., 2018; Vivanti et al., 2018).

An expanding body of empirical evidence suggests that early intervention has beneficial outcomes for parents of children with neurodevelopmental disorders, such as autism (Franz & Dawson, 2019). Studies mostly from high-income countries advocate that early identification of children at-risk for ASD can lead to earlier access to intervention (Chambers et al., 2018). Early intervention is known to result in numerous positive child outcomes, such as an increase in developmental, educational and social outcomes. Evidence also indicates that early intervention lowers the cost of care across the child's lifespan (Black et al., 2017). It is widely recognised that the intensity in the level of need in ASD families represents some of the greatest burden compared to other disabilities (Dawson-Squibb & de Vries, 2019). Subsequently, empowering parents through education and training is considered crucial, and parent education and training (PET) is globally endorsed as a first line of intervention post diagnosis (Dawson-Squibb, Davids, Harrison-Johnson, Molony, & de Vries, 2019). Furthermore, there are several psychosocial advantages for empowering parents through PET programmes including an increase in skills, renewed confidence, a decline in parental stress and an overall improvement of parental self-efficacy (PSE) levels (Hohlfeld, Harty, & Engel, 2018).

Since research indicates that early intervention for children with autism is crucial, it logically implies parental or caregiver involvement (Guralnick, 2017). In fact, empowering parents of children with ASD through parent education and training is considered best practice globally (Dawson-Squibb, Davids, Harrison-Johnson, et al., 2019). Consequently, a wide range of PET programmes exist and are developed mainly in the United States and other high income-countries (HIC), however, very few are developed and appraised outside of the United States (Dawson-Squibb, Davids, Harrison-Johnson, et al., 2019). Therefore, factors relating to the

appropriateness and acceptability of implementing a PET programme in a low-resource setting is important.

Families raising a child diagnosed with autism often face a discrepancy between their need for services and the availability thereof, typically because they are on long waiting lists for services (Chambers et al., 2017; Franz et al., 2018). As a LMIC, South Africa is known to have limited access to evidence-based autism services; expertise is limited and high-quality training is difficult to access (De Vries, 2016; Guler et al., 2018). According to Abubakar (2016) and De Vries and colleagues (2016), the likelihood that there will ever be sufficient skilled therapists to provide individual intervention with children with autism in Africa is improbable. There is a plethora of research from Western, high-income countries which have found that if parents are trained, they can act as a facilitator for positive change for their child (Germansky, Reichow, Martin, & Snyder, 2020; Hampton & Kaiser, 2016; Hohlfeld et al., 2018; Ingersoll & Wainer, 2013; Tosh, Arnott, & Scarinci, 2017). Since caregivers often spend the most time with their children, teaching parents language facilitation strategies provides more opportunities to maximise positive child language outcomes (Landa, 2018; Roberts & Kaiser, 2015). Furthermore, the home context is a familiar one to the child and the parent is a familiar communication partner (Kaiser & Roberts, 2013). Teaching parents is likely to lead to generalization of skills to the home context. Additionally, studies report that parent training leads to increased parental knowledge of autism, improved child communicative behaviour, enhanced parent communication style and increased parent-child interaction and higher levels of parental satisfaction (Hohlfeld et al., 2018; McConachie & Diggle, 2007; Tosh et al., 2017).

It is known that spoken-language deficits are core to many children with autism spectrum disorder who frequently present with delays in this area. To address these challenges early intervention programmes involving both parent and clinician have been found to be effective in improving language outcomes for children with ASD (Hampton & Kaiser, 2016). In South Africa, parent programmes available typically involve biweekly, one-on-one (high intensity) coaching sessions which are often costly and time consuming. This can place an unnecessary treatment burden on parents and carers from low-resource contexts and would be unsustainable in the majority of LMICs(De Vries, 2016). Parents and caregivers of children with autism reported higher rates of caregiver stress related to economic and emotional burden of care in comparison to families of other developmental disabilities (Guler et al., 2018). Hence, a range of ultra-low intensity parent education interventions, such as group PET programmes should be explored to cater for families, especially those residing in low-resourced communities.

According to De Vries (2016) it is pivotal to develop a collection of empirically based PET programmes, delivered by a range of professionals in appropriate and feasible ways to families and their children with autism in low-resourced communities while ensuring implementation fidelity. Concerns related to the cultural appropriateness of delivering standardised parent education and coaching programmes originating from high-income countries to families of low socio-economic background, such as those in the Western Cape of South Africa has been discussed by De Vries (2016) and Dawson-Squibb et.al (2019). It is advisable for the tool or programme to be piloted and evaluated in the community of interest to identify bias associated with language, socially related activities and materials, this will determine parental acceptance of the programme. However, relatively little evidence-based research demonstrates 1) the effectiveness of group caregiver skills training developed in LMIC and adapted in this context; or 2) locally developed PET programmes; 3) or locally developed early intervention programmes.

Implementing low-intensity interventions, such as group-based PET training, is a cost and time effective way of providing intervention for children with autism spectrum disorder who have been recently diagnosed and who live in in LMICs (Tomlinson et al., 2014). There is an urgent need and an ethical obligation for researchers to develop sound post-diagnostic early interventions for resource-limited environments. Additionally, South Africa needs culturally appropriate PET programmes to meet the needs of its families in low cost, high-impact ways. Typically, a large number of PET programmes focus primarily on teaching parents to manage their child's challenging behaviour and in comparison very few focused primarily on improving parental self-efficacy (PSE) or social-communication (Hohlfeld et al., 2018). Many PET programmes incorporated PSE and communication as one of many other components addressed, but do not specifically focus largely on these areas. The primary research aim for this study was therefore to develop and implement a brief low-cost group-based parent education and training programme to evaluate its effectiveness in improving parents social-communication skills and feelings of competence.

### 1.3. Chapter Outlines

This dissertation comprises six chapters. *Chapter 1* introduces the study and presents an outline of each chapter. This chapter also provides an explanation of important terms and abbreviations used in the dissertation. *Chapter 2* provides a detailed discussion of the theoretical background for this study. This chapter discusses the increasing prevalence of autism spectrum disorders

and the escalating strain the disorder places on families and services worldwide, with particular focus on low-and middle-income countries such as South Africa. The chapter further delves into the theoretical underpinnings of and types of parent education and training programmes, as well as addresses the research-to-practice gap concerning the lack of early interventions that are accessible and culturally appropriate in low-resource communities. The chapter also highlights issues in the literature relating to the unmet needs of parents and discusses the definition of self-efficacy and factors contributing towards the development of these beliefs. It expands on the benefits of group-based parent education and training and teaching parents key strategies to develop social-communication skills. *Chapter 3* outlines the methodology and procedures of this research study. This chapter discusses the aims, design, participants, material development and data collection procedures of the current study. *Chapter 4* presents the results of Phase 2 of the study (the stakeholder perspectives) research study. This chapter presents the development of the COMPAS materials and training activities and describes the core communication strategies included in the training. The effectiveness of the training programme is established and the results from Phase 3 of the study (implementation of the COMPAS programme) sample population are analysed are presented in *Chapter 5*. *Chapter 6* offers a critical discussion of the results and presents the strengths and limitations of the current study. This chapter concludes with recommendations for future research.

## 1.4. Definition of Key Terms

Below is a list of the key terms (and their definitions) which are used in this dissertation:

### Acceptability

How attractive and agreeable an intervention would be in a diverse service setting (Lewis, Weiner, Stanick, & Fischer, 2015).

### Appropriateness

Refers to the extent to which an intervention is fitting for a particular population (Lewis et al., 2015).

**Autism Spectrum Disorder**

"The lives of individuals affected by ASD are compromised in a number of ways as the symptoms of ASD affect three areas of functioning, including (1) social interaction and social communication, (2) language development, and (3) restricted, repetitive, and stereotyped patterns of behaviour" (American Psychiatric Association, 2013, p.50-56).

**Early Intervention**

"Early intervention refers to programmes that are designed to enhance the developmental competence of participants or minimize delays. Children targeted for early intervention may either include environmentally or biologically vulnerable children, or those with established developmental deficits. Early intervention is designed to capitalize on experience-dependent neuroplasticity, a fundamental property of the brain, by which neuronal connections are created and organized, and learning occurs in response to a child's experiences with the environment" (Landa, 2018, p.2).

**Fidelity**

Relates to the extent to which individuals are able to competently implement an intervention as it was designed (Olswang & Prelock, 2015).

**Implementation Science**

"Implementation science is the study of methods used to promote systematic uptake of research into routine clinical practice and to improve patient outcomes and service quality" (Douglas, 2019, p.1).

**Intellectual Disability**

"Intellectual disability is a disorder with onset during the developmental period. It is characterised by intellectual deficits and difficulty functioning in daily life areas such as communication, personal self-care, home living, social skills, academics, work, leisure, health and safety" (American Psychiatric Association, 2013, p.33-36).

### Low- and Middle-Income Countries

The World Bank income classification is based on national income per person, the first World Development Report introduced groupings of "low income" and "middle income" countries using a threshold of $250 per capita income as a threshold between the groups" (World Bank, 2018).

### Naturalistic Developmental Behavioural Interventions

Naturalistic Developmental Behavioural Interventions "are a group of interventions which implemented in natural settings, involve shared control between child and therapist, utilize natural contingencies, and use a variety of behavioural strategies to teach developmentally appropriate and prerequisite skills" (Schreibman et al., 2015, p.2411).

### Parent Education and Training

"PET was defined as programmes that pass on information and/or skills to parents/carers using a range of modalities (didactic, role play, discussions, video guidance, and so on) in a setting where parents/carers and trained facilitators are the direct participants" (Dawson-Squibb et al., 2019, p.2).

### Stakeholders

Any individual or group who may be involved in designing, giving, receiving or administering the intervention service being evaluated, or who might be affected by it (Palys, 2008).

## 1.5. Common Abbreviations

Below is a list of the common abbreviations used in this dissertation:

**ASD** Autism Spectrum Disorder

**CDC** Centers for Disease Control

**COMPAS** Communication Parenting Strategies

**EB** Early Bird

**EBP** Early Bird Plus

**ECBI** Eyberg Child Behavior Inventory (Eyberg & Pincus, 1999)

**ECI** Early Childhood Intervention

| | |
|---|---|
| **ECD** | Early Childhood Development |
| **EMT** | Enhanced Milieu Teaching |
| **ESDM** | Early Start Denver Model |
| **ID** | Intellectual Disabilities |
| **HIC** | High-income countries |
| **JASPER** | Joint Attention Symbolic Play Engagement and Regulation |
| **LMIC** | Low and middle-income countries |
| **NDBI** | Naturalistic Developmental Behavioural Interventions |
| **PT** | Parent Training |
| **PET** | Parent education and training |
| **PICCOLO** | Parenting Interactions with Children: Checklist of Observations Linked to Outcomes (Anderson, Roggman, Innocenti, & Cook, 2013) |
| **PLS-5** | Preschool Language Scale 5$^{th}$ Edition (Zimmerman, Steiner, & Pond, 2011) |
| **PSE** | Parental self-efficacy |
| **PSEMI** | Parenting self-efficacy measuring instrument (Harty, 2009) |
| **PSOC** | Parenting sense of competence (Gibaud-Wattston & Wandersman, 1978) |
| **RC** | Reliable Change |
| **RCT** | Randomised Control Trial |
| **REP** | Replicating Effective Programs |
| **SCERTS** | Social Communication/Emotion Regulation/Transactional Support |
| **SE** | Self-Efficacy |
| **SLT** | Speech and Language Therapist |
| **SSA** | Sub-Saharan Africa |
| **VIF** | Variance Inflation Factor |
| **WCED** | Western Cape Education Department |

**WHO** World Health Organisation

# Chapter: 2

# Literature Review

## 2.1. Introduction

In this chapter the theoretical framework and principles which shaped the research question and design are discussed. This chapter highlights autism as a global public health concern and identifies the challenges of early identification as well as early intervention for autism spectrum disorders (ASD) in low- and middle-income countries (LMICs). It highlights the persisting disparities in early intervention service provision for children with autism and their families living in resource limited contexts and discusses the value of parent education and training programmes as an important first line intervention for parents. Lastly, the role of parents as active partners in intervention is explored and the link between teaching activities and parenting self-efficacy is outlined.

## 2.2. Autism as a Global Public Health Challenge

The estimated prevalence of children under 5 living with developmental disabilities is close to 53 million worldwide. Approximately 95% (about 50 million) of these children live in LMICs (Olusanya et al., 2018). Although the prevalence of developmental disorders for children younger than 5 has decreased in most regions, the rates of children with developmental disabilities have increased substantially in Sub-Saharan Africa by just over 71% between the period of 1990 – 2016 (Olusanya et al., 2018). Estimates taken from the 2016 Lancet series on Early Childhood Development indicate that 250 million children under 5 years in low-income and middle-income countries are at risk for not reaching their developmental potential (Black et al., 2017). These staggering figures, which demonstrate insignificant improvement in the developmental potential of young children in LMICs, have attracted global attention to the existing burden developmental disabilities, including autism spectrum disorder places on resource limited countries, specifically Sub-Saharan Africa.

Boyd et al. (2010) affirm that “the greatest change in the diagnostic demographics of developmental disabilities in the last 25 years is the emergence of autism spectrum disorders (ASD) as a primary disability condition” (p.75). Formerly considered a low-prevalence disorder, ASD is currently one of the leading neurodevelopmental conditions affecting 1% of the world’s population (Franz et al., 2018; Guler et al., 2018; Louw, Bentley, Sorsdahl, &

Adnams, 2013). The Centers for Disease Control and Prevention (CDC) reports that the prevalence for autism spectrum disorder is 1 in 59 among children under the age of 8 (Baio, 2018; Ruparelia et al., 2016). Consistent with previous reports, boys are four times more likely to be diagnosed with ASD than girls, the rate is 1 in 38 among boys and 1 in 152 among girls (Baio, 2018). Additionally, researchers report that over 60% of individuals with ASD present with co-morbid intellectual disability (Abubakar, Ssewanyana, de Vries, et al., 2016). Autism Spectrum Disorders (ASD) characteristically develops in early childhood and persists throughout adulthood. It is a complex, neurodevelopmental disorder. The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) characterises autism by deficits in the development of communication and social interaction, as well as the appearance of restricted and repetitive behaviours, with onset in the first 3 years of life (American Psychiatric Association, 2013). ASD is associated with a wide range of impairments ranging from psychiatric disturbances to significant interferences with educational, occupational and social life. ASD has also been reported to co-occur with specific strengths such as visual-spatial skills and attention to detail (Mahdi et al., 2018). The precise aetiology of autism spectrum disorders is unknown, however according to Dillenburger (2015) it is highly likely to originate from a combination of genetic and environmental risk factors. According to research from high-income countries the prevalence of autism across racial, ethnic and socio-economic groups does not seem to be disproportionately represented (Boyd et al., 2010; Prelock, Calhoun, Morris, & Platt, 2011; Stone & Yoder, 2001). As there is no cure for autism, these persistent, combined deficits frequently have an adverse effect on the affected individual's quality of life as well as that of their families (Abubakar, Ssewanyana, de Vries, et al., 2016; Boyd et al., 2010; Louw et al., 2013).

Communication is a core deficit of ASD, difficulties include problems with words, sentence comprehension and prosody. A combination of these problems hinders the production and understanding of speech and language (Tager-Flusberg, 2016). It is estimated that in the paediatric population under 5 years of age, between 16% and 21% experience speech or language difficulties, with up to 50% of these children presenting challenges in both areas (Tosh et al., 2017). Specifically in ASD, 50% of children do not develop sufficient meaningful speech by age 3 and at least 30% of all children with ASD will remain minimally verbal following interventions (Abubakar, Ssewanyana, de Vries, et al., 2016; Baio, 2018; Hampton & Kaiser, 2016). According to Yosick and colleagues (2016), the development of functional language skills is an essential focus of treatment in children with autism for several reasons. A

child who is unable to communicate his basic wants and needs to parents and carers may resort to engaging in challenging behaviour, such as temper tantrums and self-injurious behaviour. Furthermore, improving language abilities may also lead to improvement in other social and cognitive abilities. Additionally, demonstration of meaningful speech in the pre-school years is predictive of later adult outcomes in individuals with autism (Yosick, Rachel et al., 2016). Finally, raising an autistic child who is non-verbal is associated with high levels of stress in families due to their inability to communicate their needs (Yosick, Rachel et al., 2016).

A consequence of the substantial increase in the prevalence rate has resulted in a heightened realisation of the burgeoning strain that the disorder places on the affected individuals, their families as well as existing services worldwide (CDC, 2014; Malcolm-Smith, Hoogenhout, Ing, Thomas, & De Vries, 2013). According to recent studies the burden represented by this disability is currently underestimated in Africa and other low- and middle-income countries, since the documented prevalence of autism in these regions remains unclear. Guler et al. (2018) in their recent comprehensive review of the literature confirm that to date no populace-based prevalence studies have been conducted in Africa due in part to the scarcity of validated and culturally sensitive diagnostic tools. Abubakar et al. (2016) rigorously reviewed all ASD literature conducted in SSA over the past 50 years and acknowledged that there is a dearth of scientific, robust published epidemiological studies making it challenging to estimate the precise prevalence of ASD in SSA. Although there is scarcity of locally published literature, researchers postulate that there is no reason to believe that rates of autism will be lower in SSA, than in the rest of the world (De Vries, 2016; Franz et al., 2018).

In 2014, the World Health Organisation (World Health Organization, 2013) recognised developmental disabilities, including autism as a global public health challenge. This specialised agency concerned with public health adopted a resolution supported by all member states including South Africa, calling for the development and implementation of national policies which affiliate with the needs of persons with ASD and best practice guidelines that are evidence based (Franz et al., 2018). Policies are crucial because they reflect the commitment from government and policy makers in galvanising the required attention and support required for the affected children and their families (Olusanya et al., 2018).

Increased public awareness and knowledge about autism plays a role in generating pressures from families and policy makers for further information about the disorder, access to appropriate diagnostic services and the development and availability of post-diagnostic

interventions (Abubakar, Ssewanyana, de Vries, et al., 2016). Although there has been substantial progress in creating awareness of autism in low- and-middle income countries in recent years, common significant challenges still affect families on account of limited awareness in sub-Saharan Africa (SSA), particularly those living in rural areas (De Vries, 2016). Without sufficient awareness about autism, families may not seek or be referred to appropriately skilled medical practitioners for proper assessment and diagnosis. Abubakar (2016) and colleagues denoted that race and ethnicity, as well as socio-economic factors can further adversely affect the age at which children are diagnosed. These factors (singly or in combination) result in children from lower wage groups or rural households often being diagnosed at later ages (Abubakar, Ssewanyana, de Vries, et al., 2016). Later identification of ASD potentially denies children the right to quality early intervention services. Despite considerable progress in early childhood development research and intervention programmes, intervention services remain of varying quality with uncoordinated and inequitable access, particularly for children younger than three years (Black et al., 2017; De Vries, 2016; Franz et al., 2018).

### 2.3. Autism Identification and Intervention in South Africa

Scientific knowledge of ASD has increased on a global scale in recent years and recent efforts by the World Health Organization to raise awareness about the need for ASD services is notable. However, most of the research within the field of neurodevelopmental disabilities comes from the United States, the United Kingdom and other high-income countries (De Vries, 2016; Makombe et al., 2019; Reichow, 2012). This is despite the fact that 90% of those living with the disorder come from LMICs, such as Africa (Chambers et al., 2018; De Vries, 2016; Malcolm-Smith et al., 2013; Mthombeni & Nwoye, 2018; Schlebusch et al., 2016). Therefore, a substantial gap in understanding the majority of the global ASD population still exists.

Africa is the second largest continent in the world and also the poorest. Sub-Saharan Africa has a population of almost 1 billion people, 40% of whom are children under the age of 14 years (Abubakar, Ssewanyana, de Vries, et al., 2016; De Vries, 2016; Guler et al., 2018). South Africa is the southernmost tip of the African continent and has a population base of over 55 million. As a LMIC, the majority of services from health and social care organisations are limited and the growing prevalence rate of autism poses a heavy burden on this developing country (Franz et al., 2018).

Access to quality health care and poverty are two of the major national health challenges in South Africa. It is acknowledged that in the 20 years since apartheid, considerable progress has been made toward reversing discriminatory practices and improving aspects of health in South Africa (Mayosi et al., 2014). Yet the health and well-being of majority of South Africans remains stricken by a persisting burden of contagious and non-communicable diseases and inadequate human, physical and fiscal resources to meet the needs of a growing population with a rising stream of refugees and migrants. Extreme poverty affects a large proportion of the population in South Africa (Mayosi et al., 2014). Furthermore, more than 40% of all South African families are headed by a single bread winner, in most instances it is the woman and the number of families who have a living, but absent father, is increasing (Schlebusch et al., 2016). According to (Mayosi et al., 2014) health should be considered within the broader context of wealth as they are directly and indirectly related. Both relative and absolute poverty in South Africa are relevant and share common causes and manifestations with poverty around the globe. The elimination of discriminatory apartheid legislature has resulted in expanding economic growth for the country and an increase in social grants for the poorest and unemployed of the population. Despite social grants alleviating some of the challenges surrounding abject poverty, 45% of the population still lives on less than $2 per day and more than 10 million people live on less than $1 dollar per day, below the 'food poverty' line meaning that people are unable to purchase sufficient food for a sustainable diet (Mayosi et al., 2014). Between 1995 and 2009, poverty in South Africa had become worse, the top 10% of the South African population earned 58% of the total annual national income, in contrast the bottom 70% combined earned a meagre 17% (Mayosi et al., 2014). These social and economic disparities are among the largest in the world and are aligned with diseases of poverty. Poverty and adverse childhood experiences can have long-term effects by disrupting brain development and cognition (Black et al., 2017). However, longitudinal follow-up studies among children exposed to poverty and other adverse conditions of deprivation, have shown positive effects of early intervention programmes on later adult outcomes. These findings provide strong justification for global economic investment in early childhood intervention programmes (Doyle, Harmon, Heckman, & Tremblay, 2009; Hoddinott, Alderman, Behrman, Haddad, & Horton, 2013; Maluccio et al., 2009; Walker, Chang, Vera-Hernandez, & Grantham-McGregor, 2011).

Striking disparities in the provision of public health care continue to widen in South Africa. As stated, the national public health sector is marked by wide disparities; it provides care for 84%

of the population, but is staffed by 30% of the medical personnel in the country (Guler et al., 2018; Malcolm-Smith et al., 2013; Mayosi et al., 2014). Furthermore, the national public health sector employs approximately 30% of the doctors in the country and remains the only provider of health care for more than 40 million people who do not have medical insurance and who constitute over 80% of the national population. Mayosi and colleagues (2014) estimate the majority of state funded hospitals are in a state of disrepair and crises. In direct contrast with this, 70% of doctors work full-time in the private sector providing access to health care for the 8 million South Africans (16% of the population) who have private medical insurance (Mayosi et al., 2014). Additionally, up to 25% of the population who are uninsured but pay out of pocket for private health care services (Mayosi et al., 2014). Therefore, the majority of the population do not have access to private medical services, most of the country relies on state health services which are mostly functioning at maximum capacity.

The extreme financial burden on black South African caregivers needing to access health care treatments for their children with autism has been well documented in a recent study by (Mthombeni & Nwoye, 2018). In some cases, these excessive financial burdens, meant that caregivers had to request financial assistance from family members to cover treatment expenses (i.e. therapeutic intervention sessions, multiple trips to and from service providers). While caregivers had to make various significant sacrifices, one major challenge encountered was having to spend large sums of money in an effort to access various health care providers from different sites (Mthombeni & Nwoye, 2018). These combined socio-economic challenges place an unbearable burden of care on families raising a child with autism in South Africa. These data highlight the need for accessible, co-ordinated services for families of children with autism in South Africa.

In addition to the challenges related to accessing adequate health care services, limited policies at national and provincial level cripple the attempt to co-ordinate services for children with ASD and their families. Mokitimi and colleagues (2018) recently evaluated the state of child and adolescent mental health policy development and found that there is no national autism spectrum disorder (ASD) policy, but rather a general policy exists on early detection and intervention, known as the National Integrated Early Childhood Development Policy of 2015 (Mokitimi et al., 2018). This policy describes the commitment of the South African government to provide an inclusive package of Early Childhood Development (ECD) services to all young children by 2030. Presently, the Western Cape Department of Health (DoH) and Department of Social Development (DSD) regard ASD as part of the cluster of general developmental

disabilities and not as a ‘stand-alone’ disorder, therefore ASD specific early identification and intervention may not coincide with DoH and DSD goals (Franz et al., 2018; Mokitimi et al., 2018). To the best of our knowledge no African country has published policies or good practice standards for autism assessment, treatment, education and support (De Vries, 2016; Franz, Chambers, von Isenburg, & de Vries, 2017; Gona et al., 2016; Tilahun et al., 2016). Given this policy landscape, it is not surprising to discover that in the period 1978 to 2015 only 28 intervention studies and no early intervention studies for children with ASD in SA were published (Franz et al., 2017).

The cost related to the processes involved in confirming a formal diagnosis of ASD, also impacts on the limited access to early intervention in the SA context. International literature from resource-rich countries estimate that annually over 7 billion dollars is shouldered by individuals with ASD, their families, communities and the government (Horlin, Falkmer, Parsons, Albrecht, & Falkmer, 2014). A definitive diagnosis of ASD is made by experienced members of a multi-disciplinary team (MDT) who rely on observable behaviours using valid ‘gold standard’ diagnostic procedures, in conjunction with obtaining historical data and parental input (Dillenburger, 2015; Horlin et al., 2014). Surprisingly, in high-income countries such as the United Kingdom, the mean age of ASD diagnosis is at 55 months, with only 10% of children being diagnosed under 3 years of age (Franz et al., 2018). The situation is very similar in low-resourced environments, later screening and identification of possible autistic features, coupled with a dire lack of access to services, often dictates that the mean age of diagnosis is over 4 years of age (Lord et al., 2006). Horlin and colleagues (2014) further state that costs of autism are expected to climax during the time a diagnosis is being confirmed and when early intensive interventions are being administered. Unfortunately for these individuals and their families many costs are on-going and remain a life-long burden to be borne. Unsurprisingly, research conducted in resource-rich countries suggest that early diagnosis of ASD in a child may reduce the overall cost of ASD, since early diagnosis is likely to lead to early intervention which frequently results in better overall social and educational outcomes (Franz et al., 2018; Guler et al., 2018) and a reduction in the life-long costs associated with autism.

The detailed process of obtaining a diagnosis and the struggle to access intervention services as outlined above is illustrated using processes from one province, namely the Western Cape (the province in which this study is conducted). The Western Cape Province is recognised as one of the better-resourced in terms of health care in South Africa. Typically, prior to a clinical

diagnosis of ASD being confirmed, a developmental delay, is identified at a primary care level, such as a local clinic. A referral is then made to a state paediatric neurodevelopmental clinic at a tertiary hospital, where the waiting period for a formal diagnosis of autism typically can be 9 to 18 months (Franz et al., 2018). Subsequent to a confirmation of a diagnosis, the child would be referred for therapy at the nearest state hospital. A referral form is completed by a health professional, (typically the doctor who confirms the diagnosis). This referral is sent to the administrator of the Western Cape Education Department's (WCED) consolidated waiting list for public sector special needs services and school placement (Franz et al., 2018; Guler et al., 2018). When children turn 7 years of age, they should be placed at a school which can accommodate their educational needs. In the interim, some children may be able to access services through the tertiary hospital. However, those children with ASD who do have access to state services (such as speech and language therapy and occupational therapy), receive these services infrequently (Malcolm-smith, Hoogenhout, Thomas, & Vries, 2013). Therapeutic services differ widely across the province, generally children with ASD who receive access to state therapeutic services, receive a single 30-minute session of speech therapy and occupational therapy as infrequently as every four to six weeks, with the burden of ongoing support falling to the parents or caregivers (Franz et al., 2018; Guler et al., 2018). Waiting lists for state therapeutic services can be up to 6 months and many children with autism do not receive these services at all possibly due to socio-economic barriers, funding for transport being one of the major challenges (Malcolm-Smith et al., 2013; Mthombeni & Nwoye, 2018). This illustrates that, even in the Western Cape (one of South Africa's most resourced provinces) specialised paediatric clinical services are not readily available to low- and middle-income families and existing clinical services are overburdened (De Vries, 2016; Franz et al., 2018).

The conception and development of the waiting list is discussed next as an illustration of the need for co-ordinated and integrated care pathways for families of children with autism. As a consequence of the increasing number of young children being diagnosed with autism, in 2010, the WCED, a major provincial state department responsible for public schooling and education attempted to establish a provincial consolidated database (herein referred to as the waiting list) of all children within the Western Cape who had a confirmed or suspected diagnosis of ASD and were awaiting special educational services. To our knowledge the conceptualisation and establishment of a central database for all children with autism requiring assessment, intervention and school placement was the first of its kind within South Africa. At the start of this initiative approximately 50 young children were observed, assessed and diagnosed with

ASD by a state appointed multi-disciplinary team. This team consisted of an occupational therapist, speech therapist, psychologist and an educator, and all had extensive experience working in the field of ASD. Following assessment, the children's details were added to the WCED's consolidated database to await being placed in an autism specific school environment. In 2016, 940 children with ASD were identified in special schools in the Western Cape, and 744 were awaiting educational services (school placement), of which 338 children were of legal school going age (7 years and above) and were not yet in schools, the remaining 406 children were 5 years and under (ECD age cohort) (Pillay, Duncan, & Vries, 2018). The investigation of the waiting list by Pillay et al. (2018) demonstrated alarmingly high rates of children with autism waiting for school placement in the Western Cape of South Africa. The catchment area for this waiting list is supposed to be representative of the entire Western Cape Province, however this is highly dependent on the availability of health professionals to identify and refer children to the ASD data base (Franz et al., 2018). Furthermore, the 940 children identified in the examination of the data base represents a rate of less than 0.1%, considerably lower than the expected prevalence (Pillay et al., 2018). In a recent examination of the waiting list, the majority of provinces were represented, the results showed that between 2012 and 2016, there was a 276% increase in the number of children with ASD on the WCED's waiting list (Pillay, Duncan, & Vries, 2019). There is presently no published information from other provinces on early identification, early intervention approaches and or provincial waiting lists for ASD schooling (Franz et al., 2018). In South Africa the constitution dictates that school-going age is at 7 years, therefore no public-sector special school is expected to accept the child with autism prior to them becoming of school going age (Guler et al., 2018). Therefore, intervention during the critical period for language and speech development prior to age 7, has not been utilised to its fullest. Intervening in the early years predicts a more promising trajectory of development (Black et al., 2017). South Africa has nine government based ASD specific schools, six of these schools are in the Western Cape, two are in Gauteng and one is located in the Eastern Cape. Positively, once placed in an autism specific school, children with ASD will be able to access some therapeutic services such as speech therapy and occupational therapy. It is evident that given the small number of schools in contrast with a population of 52 million people, many children with ASD will be unable to be placed in these educational facilities (Franz et al., 2018). The present situation in the Western Cape is that the majority of ASD specific schools and ASD units (classrooms attached to general special needs schools) are mostly full or lack the physical environmental space to accommodate additional classrooms being built for learners with autism. Educational placement for the children who remain on the

growing waiting list for therapeutic services rendered by the Department of Health is limited, as most government services are already functioning at maximum capacity (Malcolm-Smith et al., 2013). Typically, ASD specific schools in South Africa do not provide early identification or long-term intervention services, given that the legal age for school placement is 7 years old (Franz et al., 2018). The sad reality is that most children with ASD will therefore only be considered for an assessment and suitable educational placement in an ASD specific environment once they turn 7, this is notwithstanding that the WCED's waiting list for educational services continues to grow at an alarming rate. Unfortunately in South Africa no government pre-schools exist and private sector special education pre-schools vary in quality, cost and many do not provide evidence-based services (De Vries, 2016; Guler et al., 2018; Malcolm-Smith et al., 2013).

As a low and middle-income country, the majority of services from health and social care organisations are limited and the growing prevalence rate of autism poses a heavy burden on South Africa. Access to quality health care and poverty are two of the major national health challenges in this developing country. Therefore, costs of current and future ASD interventions will be an important factor to consider in this setting, where families have limited financial resources (Guler et al., 2018; Mayosi et al., 2014).

## 2.4. The Importance of Early Intervention for Children with ASD and other Developmental Disabilities

In South Africa there is lack of published data on the topic of early intervention on children with ASD. A plethora of research studies affirm that the earlier intervention occurs in a child's life, the better the outcomes (Handy, Castro, & Loscalzo, 2011; Raab & Dunst, 2004; Reichow, 2012; Schreibman et al., 2015). The long-term benefits of access to early diagnosis and intervention for ASD are multiple. Firstly, between birth and six years of age the brain is extremely receptive to develop social and language skills. Teaching social and language skills early in life is associated with more rapid and sustained learning as opposed to when skills are taught later in life (Black et al., 2017; Franz & Dawson, 2019; Paul, 2011). Secondly, high quality, early intervention results in individuals with ASD possessing better social aptitude, language and independence skills, therefore creating a greater chance of being broadly integrated into society (Hohlfeld et al., 2018). This has a cumulative effect of decreasing the long-term costs of special education, sheltered living and employment (Franz et al., 2018).

Thirdly, early identification and intervention creates crucial opportunities to increase empowerment of families and caregivers, decrease parental stress and increase parental self-efficacy (PSE) levels (Franz et al., 2018; Hohlfeld et al., 2018; Siller et al., 2013). Considering that autism is a life-long disorder the goal of early intervention is to increase the child's optimal functioning by minimising core features and deficits in areas of development by increasing adaptive functioning (Louw et al., 2013). Recent studies conclude that these gains are usually acquired when intensive intervention is incorporated into the child's life from a young age, usually between the ages of 2 and 4 years (Black et al., 2017; Franz et al., 2018; Hohlfeld et al., 2018). Intervening in the early years of life is more likely for individuals living in high-income countries due to the promising growth of scientific knowledge which has resulted in children being screened and diagnosed and given access to evidence-based intervention programmes. Unfortunately this is not the case in South Africa (SA), since ASD intervention services in the public sector are extremely limited (De Vries, 2016; Guler et al., 2018; Malcolm-Smith et al., 2013; Tekola et al., 2016).

Empirically based development models advocate for the necessity of early experience and greater malleability in early childhood development in support of early intervention services for at risk children and their families (Guralnick, 2011). Children with developmental disabilities could belong to various diagnostic categories including developmental delay, cerebral palsy or autism spectrum disorder (Hamid et al., 2020; Taheri, Perry, & Minnes, 2016, 2017). In addition to the variation in diagnostic categories, children with developmental disabilities present with wide-ranging differences in their presenting characteristics as well as diverse family dynamics (Guralnick, 2011). As a result early intervention protocols must reflect an unusual level of diversity to respect the theoretical frameworks, goals and intervention approaches (Guralnick, 2011).

Child development is dependent on many contributing factors, many of which are profoundly affected in children living in LMIC. Three features of parenting that have been consistently related to children's overall cognitive and emotional well-being, these being; (1) cognitive stimulation, (2) parent sensitivity and responsiveness to their child, (3) parent emotional affect (Louw et al., 2013). Caregivers and parents of children in LMIC often have chronic poor health and live in poverty in overcrowded residences. Given the challenging circumstances parents face, these factors will impair the parent's ability to provide basic care and stimulation for their child. Furthermore, their sensitivity and response rates towards their child are poorer in comparison to parents from developed countries (Tomlinson et al., 2014). Research suggests

that early cognitive stimulation increases cognitive abilities ((Einfeld et al., 2012; Guralnick, 2011; Raab & Dunst, 2004).

Early intervention programmes have been shown to improve the developmental trajectory of the young child with developmental disabilities including, ASD (Taheri et al., 2016, 2017). Extensive evidence exists showing the benefits of early intervention with children with DD, these include improved motor, cognitive, social and communication skills, as well as decreased atypical behaviours (Einfeld et al., 2012; Guralnick, 2011; Raab & Dunst, 2004; Tomlinson et al., 2014). Moreover, research shows that early intervention results in enhancing children's outcomes and these are related to components associated with family patterns of interaction (Guralnick, 2017).Therefore, programmes directed at enhancing the capacity of parents to foster the cognitive and social development of their children with intellectual disabilities should be implemented, particularly in LMICs where children living with disabilities are more common (Einfeld et al., 2012; Hartley & Newton, 2009). Impairments in social-communication are a core deficit of individuals with ASD which makes verbal communication and social interactions with peers far more challenging (Taheri et al., 2016). In their study Taheri et al., (2016) reported that children with intellectual disability and autism participated in fewer social activities than their neurotypical peers. Furthermore, the ability to use language and symbolic play during constructive play activities in children with DD were significantly delayed in comparison to their neurotypical peers (Taheri et al., 2016). Children with DD who have delayed communication skills, reduced participation in social activities and peer relationships are at a disadvantage for social growth and quality of life (Taheri et al., 2016).

Recent research has indicated a dire need for effective early intervention services across diverse community settings that are beneficial to families and their children (Handy et al., 2011). Families, especially caregivers have an important role to play in shaping a child's communication outcomes. The process of communication begins from an infant's earliest interaction with their caregivers to later more sophisticated and refined dialogue (Kaiser, 2014; Stone & Yoder, 2001). According to Kaiser and Gray (1993) during the early stages of life, infants and caregivers share emotional states. One of the ways that this is achieved is by seeking information from the caregiver by use of eye-contact (social referencing). Later, this evolves to a stage where the infant and caregiver share attention to each other while including objects or events into this shared attention. This behaviour is known as joint attention. Several studies have suggested that there is a strong causal relationship between the development of these earlier non-verbal behaviours (pragmatic skills) and language development (Bottema-Beutel et

al., 2018; Hancock & Kaiser, 2003; Yoder, Spruytenburg, Edwards, & Davies, 1995). Pragmatic skills are established before the development of verbal language and include abilities such as eye-contact, joint attention, imitation and turn-taking, these typically develop within the first 12 months of life (Hancock & Kaiser, 2003). The presence of these pre-linguistic skills may positively affect the relationship between early intervention programmes and long-term language outcomes (Ingersoll, 2008). There is a strong shift towards supporting the use of a naturalistic approach to language learning for children with developmental disabilities and ASD (Raab & Dunst, 2004). This includes working within the home context and teaching caregivers' skills to enhance their everyday interactions with their child.

Early intervention aims to accelerate the rate of child learning, facilitate new development and generalisation of skills and diminish the effects of ASD on development by maximising the benefit of experience-dependent neuroplasticity (Landa, 2018). In addition to the extensive benefits early intervention services have for this population of vulnerable children, it also decreases long-term financial and societal burdens (Tomlinson et al., 2014). However, in LMICslike South Africa, a multitude of barriers exist to accessing effective early intervention services, one such hinderance is that there are insufficient skilled therapists to provide individual intervention for children with developmental disabilities (Makombe et al., 2019; Tomlinson et al., 2014). There is systematic evidence that teaching parents specific strategies to support their child's development can be effective since every child has a parent or carer (Kaiser & Hancock, 2003). Using parents to target skills in a naturalistic setting supports generalisation and the development of pragmatic skills as these form the foundation of verbal language acquisition (Raab & Dunst, 2004). The following section will provide an overview of literature pertaining to teaching parents' strategies for early intervention.

There is an accumulation of evidence proving that early intensive behavioural intervention for young children below age 5 with autism has been shown to minimise the severity of core ASD traits and has demonstrated notable long-term improvements in the areas of language development, social skills, cognition and adaptive behaviours (Black et al., 2017; Dawson-Squibb, Davids, Harrison-Johnson, et al., 2019; Franz et al., 2018; Guler et al., 2018; Hohlfeld et al., 2018). Some evidence supporting the theory of intervening early lies in the neural plasticity of the young brain, making it more susceptible to the effectiveness of ASD treatment practices (Paul, 2011; Schreibman et al., 2015). The majority of evidence-based support for the effectiveness of early ASD interventions is embedded in the implementation of intensive programmes delivered by highly trained, experienced professionals. However, considering that

South Africa is a resource-constrained environment it is unlikely that a sufficient number of highly trained therapists will ever be able to provide direct individual intervention to the children with ASD who need it (De Vries, 2016). Further, as a LMIC adhering to international best practices from HIC poses significant implementation and sustainability challenges (De Vries, 2016; Guler et al., 2018). A possible mechanism to alleviate the demand on already over-burdened services in low-resourced settings is to involve parents and caregivers in the intervention process of young children with neurodevelopmental disabilities, such as ASD (Guralnick, 2017). Estes, Swain, & Macduffie (2019) assert that best practice in the field of intervention involves parents and practitioners working collaboratively to develop child intervention goals and to ensure that parents have the skills to implement aspects of the intervention at home. By including caregivers in this process and teaching them the use of specific techniques, they would be better equipped to implement some aspects of what therapeutic services offer, creating a potentially powerful mechanism to deliver early intervention in low-resource contexts (Dunst & Trivette, 2009; Franz et al., 2018; Guler et al., 2018).

### 2.5. Benefits of Parent Education and Training in LMIC

It has been established that the majority of individuals with ASD live in low- and-middle-income countries and receive limited or no care from state health care systems. Additionally, most early ASD interventions have been developed and implemented in high-income countries, showing very little regard for the contextual factors that would need to be considered to ensure the effectiveness of these interventions in LMICs (Guler et al., 2018). Understanding the needs and perspectives of parents living in South Africa is an important step to developing and providing intervention services which are appropriate for, and acceptable to, parents of children with ASD.

In their study, Guler et al. (2018) report on parent perspectives related to early intervention services. These researchers conducted focus groups and in-depth interviews with several South African parents of young children with autism living in low- and middle-income settings in order to identify crucial contextual factors necessary for successful implementation of early ASD intervention. A few key themes identified by the researchers are presented here. Firstly, a large majority of parents reported a preference for working with university-educated professionals who had experience in working with children with autism. Most parents also expressed their preference for the language of instruction during intervention to be in English.

Equally important to note was their concern regarding the existing burdening cost of ASD interventions and that the place of intervention needed to be easily accessible, such as a home or clinic setting and intervention had to be affordable, with no 'hidden costs' in a parent community where financial resources are extremely limited. They further stated the importance of working with a therapist/clinician who would provide them with feedback on their parenting approach and teach them early intervention skills and strategies that were specific to their child. Lastly, parents stressed the need for social support as a buffer against adverse situations, such as parental stress. Another recent study was conducted by Gona and colleagues (2016) highlighted the challenges faced by parents of children with autism on the Kenyan coast. They reported similar findings in that they also described parents need for empowerment and support within their own countries and communities. They further recommended that professionals engage parents in intervention options. Likewise, a similar study, the first research of its kind in Ethiopia examined parent/caregiver perspectives of those living with an autistic child, understanding the unmet needs of these parents. Similarly, the study indicated that parents expressed a desire for professionals to assist them with information and provide parent education and training on autism, while providing them with practical strategies on helping to support their children at home (Tilahun et al., 2016).

These studies indicate that parenting a child with autism is far more challenging and stressful than raising a typically developing child and that parents need access to skills which can be tailored to their child, as well as access to social support. Some of the key benefits of participating in group intervention programmes is that parents reported feeling comforted by the common theme of autism and more inclined to share experiences with one another fostering mutual support, therefore feeling less isolated (Bearss et al., 2015; Roberts & Pickering, 2010).

An investigation of the literature indicated similar evidence which suggests that parental stress related to rearing a child with autism is mitigated by two factors. Firstly, the availability of an informal social network to provide parents with support has been documented to reduce parental stress. Secondly, inclusion in an intervention programme greatly reduced parent stress. It is evident that most parent participants in the studies expressed their need to improve their parenting skills to be better equipped to manage the challenges associated with raising a child with ASD, through the provision of social support. Group-based programmes have been documented to serve as a means of increasing social support for families as well as providing professional input simultaneously (Minjarez, Mercier, Williams, & Hardan, 2013). Thus suggesting that 1) parents are able to identify their needs relating to early intervention and 2)

parent education and training programmes may be able to address the needs highlighted by parents in LMICs (Gona et al., 2016; Guler et al., 2018; Tekola et al., 2016; Tilahun et al., 2016).

Published literature also highlights an additional number of key benefits of PET programmes (Koegel, Bimbela, & Schreibman, 1996; Minjarez et al., 2013; Scahill et al., 2016; Symon, 2001; Todd et al., 2010). The first of which is cost-effectiveness as the intervention is delivered by a trained professional thereby targeting multiple families in one setting (Einfeld et al., 2012; Tomlinson et al., 2014; Ward & Wessels, 2013). The second is that apart from providing an element of social support for parents, PET programmes have additional psychosocial advantages for the parents including decreased parental stress, increased parental empowerment and improved parental self-efficacy (PSE) levels (Hohlfeld et al., 2018). Minjarez (2013) further report that the more empowered parents are, the more successful they are in coping with daily routines and interacting with professionals. According to Koegel and colleagues (1996), another benefit of PET is that involving parents in their child's intervention has been shown to result in improved functioning and greater generalisation of skills in the child. In the South African context parent training programmes can buffer risks related to poverty (e.g. lack of responsiveness in parents and under stimulation of child development), this means that improving parent knowledge may result in a more responsive parent and as a consequence may improve child outcomes too (Prata, Lawson, & Coelho, 2018; Ward & Wessels, 2013). Additionally, sensitive and responsive caring, characterised by the parent following the child's interest and lead, without being too intrusive or controlling has significant benefits for the mother-child relationship and for infant-child development. These are crucial factors that could influence a child's communication development (Tomlinson et al., 2014). Since South Africa has a national unemployment rate of more than 25%, many families reside in poverty-stricken conditions (Schlebusch et al., 2016) and could potentially therefore benefit from inclusion in a PET programme.

### 2.6. Classification of Parent Education and Training (PET) and Implementation Barriers and Facilitators in LMIC

It is well known that young children with ASD have impairments in core areas of development such as social interaction, communication and atypical behaviour. This early pattern of difficulties in development can be challenging and stressful for parents. There is consensus that parent and caregiver skills training should take place soon after a diagnosis of ASD is

confirmed (Dawson-Squibb, Davids, Harrison-Johnson, et al., 2019; Makombe et al., 2019). Therefore, approaches that support parents to develop strategies for these delays in development should be an clear route for early intervention for autism spectrum disorders (Oono, Honey, & Mcconachie, 2013).

Within the sector of child mental health, parent training (PT) is a term well understood as being closely associated with parent-focused, evidence-based treatment for neurotypical children with disruptive behaviour. In 2014, the World Health Organisation (WHO) emphasised the importance of psychoeducation to parents and carers of children with autism (Dawson-Squibb, Davids, Harrison-Johnson, et al., 2019). In the field of ASD, the term 'parent training' has been broadly applied and is readily exemplified in the literature. It is frequently used to describe a wide variety of treatments that may or may not share common attributes. The ambiguity of the term "parent training" within the sphere of ASD may be related to the complexity and multiple deficits associated with the disorder. Providing knowledge and information to parents and caregivers is referred to in the literature by many different terms, including 'parent training', 'psychoeducation' and 'parent education'. Still, the lack of uniformity surrounding this term creates confusion amongst professionals and families alike. Moreover, it raises implications for comparing and contrasting existing PT programmes. Bearss and colleagues (2015) presented a coherent taxonomy to delineate the variants of parent training in ASD. According to the authors an initial way of broadly differentiating parent training programmes is to consider whether the programme intends to provide *indirect* benefit to the child by promoting parental support and fostering parent knowledge gains about ASD (i.e. psycho-education), or whether the design of the parent training programme is to focus on skill acquisition, where the parent is the primary intervention agent and the child is the *direct* beneficiary of treatment (i.e. parent-mediated interventions) (Bearss et al., 2015).

In an effort to further expand on the work by Bearss et al. (2015), Dawson-Squibb and colleagues (2019) rigorously investigated the literature for evidence-based studies demonstrating the range of characteristics in parent training interventions in ASD. Their successful attempt at further delineating the variants of the term in a coherent manner has assisted clinicians in distinguishing parent training programmes. They assert that in real-world practice many parenting programmes for ASD are in fact 'hybrid models' that include some 'parent support' educational outcomes focused on the parent, (including some didactic approaches such as presentations and discussions with parents); and some 'parent-mediated' child-specific educational outcomes (this includes didactic approaches, such as home visits, or

video material used to observe and guide parents on parent-child interactions). Hence, the term 'Parent Education and Training' (PET) was coined to refer to these hybrid types of parenting programmes (Dawson-Squibb, Davids, Harrison-Johnson, et al., 2019). Parent Education and Training is defined as programmes that proceeds to pass on information and/or skills to parents and carers using a variety of modalities (i.e. didactic, role-play, lectures, group and panel discussions, video guidance etc.) in a content where parents and carers are the direct participants. Therefore, the focus is not on parent-child dyads, but rather the emphasis is on transferring knowledge to parents and carers who are the participants of the programme (Dawson-Squibb, Davids, Harrison-Johnson, et al., 2019). This definition implies that the child is not present in the session room while the intervention is being conducted. Using this definition of PET interventions allows the content of 'education and training' to range from parent and family well-being which covers parent support, self-efficacy and knowledge, to information on more child-centred goals, including building skills and managing challenging behaviour (Dawson-Squibb, Davids, Harrison-Johnson, et al., 2019).

It is recognised in the literature that the functioning and quality of life of persons with ASD are highly dependent on family and parental factors, such as parent knowledge, stress and family support. There is evidence to suggest that parental factors, such as emotional well-being and parental self-efficacy can have a direct effect on adherence to PET interventions and their efficacy (Dawson-Squibb, Davids, Harrison-Johnson, et al., 2019; Dawson-Squibb, Davids, & Vries, 2019).

In low resource countries PET may be the primary and only intervention available to families. Although it is fundamental to understand the existing knowledge-base of PET programmes, most reviews of PET programmes focused primarily on studies conducted in the United States (Dawson-Squibb, Davids, Harrison-Johnson, et al., 2019; Hohlfeld et al., 2018; Makombe et al., 2019). In their review Dawson-Squibb et al. (2019), identified 37 publications, representing 32 unique PET programmes from 20 different countries, including all continents except South America. While these PET programmes all had the similar goal of dispensing knowledge and skills to parents, they differed in outcomes, delivery modalities, duration, trainer knowledge and group size. For a comprehensive understanding of the scoping review (Dawson-Squibb, Davids, Harrison-Johnson, et al., 2019) the relevant descriptive characteristics of the identified publications will be discussed next.

Out of the 20 countries included in the review, 3 (15%) represented low-or middle-income countries, while 17 (85%) were HIC (Dawson-Squibb, Davids, Harrison-Johnson, et al., 2019). The programmes were delivered using a diverse selection of modalities, this included interactive training activities, group discussion and audio-visual material. In almost half of the PET programmes the most commonly used modality was group discussions and handouts, didactic methods and audio-visual materials accounted for 30% of programmes. PET programmes showed a wide range in duration, with some lasting for 90 minutes and others 30 hours. Half of the programmes were group based, the remainder included a combination of group and individual work. PET programmes often included multiple outcomes or objectives, however over 80% of programmes focused on providing parents with positive behavioural interventions to manage challenging behaviour and 48% of programmes included components on social-communication and play, while only 2% addressed improving parental self-efficacy. The majority focus on programmes addressing behavioural difficulties may be associated with the fact that psychologists were found to be the most common practitioner delivering PET programmes. However, in a recent systematic review Hohlfeld and colleagues (2018) showed that psychologists and other healthcare professionals are successfully able to implement PET programmes that enhance parenting self-efficacy. In the systematic review by Hohlfeld et al. (2018) only 13% of other professionals with expertise in ASD were reported to deliver PET programmes.

To mitigate the effects of autism spectrum disorders on child development and family well-being, PET programmes are therefore required across the globe. Aspects relating to the implementation of such programmes in different settings therefore becomes crucial. Consequently therapist/facilitator fidelity needs to be established to ensure that programmes are delivered with consistency, in other words, the manner that they are intended. One way to ensure this is to use a manual during implementation. Manualised programmes are strongly associated with empirically supported therapies and are surmised to produce better outcomes than programmes without a curriculum as they ensure standardisation of delivery and minimize variability in programme delivery (Wyatt Kaminski, Valle, Filene, & Boyle, 2008). Dawson-Squibb and colleagues (2019) indicated that 50% of studies reported use of manuals which is important for dissemination of information as well as fidelity (Dawson-Squibb, Davids, Harrison-Johnson, et al., 2019. However, Dawson-Squibb and colleagues (2019) found that only a third of manualised PET programmes specifically commented on cultural acceptability and on the appropriateness of the PET programme for multicultural participants. Many other

factors such as cost may influence implementation, particularly in low-resourced communities (Dawson-Squibb, Davids, Harrison-Johnson, et al., 2019).

While it is positive that efforts to increase the implementation of early ASD interventions is on the rise in resource constrained countries (Rahman et al., 2016) including SSA (Makombe et al., 2019), understanding factors that act as barriers and facilitators is important for successful implementation and integration of this essential services into routine care. Researchers and therapists cannot assume that evidence-based interventions originating primarily from HIC will seamlessly integrate into diverse cultural contexts around the globe. Therefore, specific attention must be given to include local stakeholder perspectives and the local context in order for an intervention to succeed (Franz & Dawson, 2019). In order to do this implementation science must become a focus.

Implementation science is a rapidly developing field of research that plays a central role in the transfer of knowledge of effective practice into routine care settings (Ghate, 2016; Olswang & Prelock, 2015). Implementation and intervention *fidelity* refers to the extent to which an intervention or programme is delivered as intended (Carroll et al., 2007). It is through understanding and measuring whether an intervention has been implemented with fidelity that researchers can gain a clearer understanding of how and why an intervention works, and the extent to which its outcomes can be improved upon (Carroll et al., 2007; Chambers & Norton, 2019; Dunst, Trivette, & Raab, 2013).

Implementation science also considers factors such as *efficacy*; the degree to which an intervention is appropriate and reasonable (Lewis et al., 2015). Stakeholder perspectives are important to establish how satisfactory an intervention would be in a particular setting, this is considered to ascertain the *acceptability* of an intervention (Olswang & Prelock, 2015). Lastly, the *appropriateness* of an intervention is vital to consider as this relates to how well an intervention 'fits' a particular population (Lewis et al., 2015). Six major categories of strategies are identified and delineated by implementation science addressing 'grass-roots level' and 'organisational level' changes when considering the implementation and refinement of an intervention programme. At grass-roots level (bottom-up approach), exploration strategies gather information from relevant stakeholders to identify potential barriers and facilitators to implementing an intervention in a relevant context. Further, educating strategies relating to material development and fidelity measures for the potential intervention. The final four strategies; financing, managing quality, restructuring, and attending to policy are primarily

focused on organisational-level (top-down) adoption of the proposed intervention (Lewis et al., 2015). The clear importance of the role of implementation science is necessary to improve access to evidence-based care, particularly given the need in LMIC.

Two implementation challenges with current PET programmes is that (1) most professionals are not parents of children with disabilities and so there is a mismatch when using professionals as role models for demonstrating skills, such as during role play activities. (2) Some PET programmes make videos available where parents demonstrate the use of skills, but many of these parents do not live in the same country as the participants and therefore it may be hard for parent participants to identify with. To address these barriers facilitators in the COMPAS group intervention programme, were a mix of professionals and local community parents. Additionally, footage of local community parents were used during video modelling sessions to create the right kind of 'profile' for demonstrating mastery which may have seemed more attainable to the parent participants. Lastly, the use of parent facilitators likely bolstered PSE as parent facilitators have been where the current participants are and could provide a unique kind of empathy that professionals can seldom match.

### 2.7. The Role of Parental Self-Efficacy (PSE) in Parent Education and Training

There is consensus that parent empowerment through education and skills training is in keeping with international best practice standards and should be a first line intervention component following diagnosis (Dawson-Squibb, Davids, Harrison-Johnson, et al., 2019; Pickard, Rowless, & Ingersoll, 2019). Despite the important role parent mediated interventions play in early intervention services they are underutilised across many community settings (Pickard et al., 2019). In low-resource settings PET interventions may be difficult to implement broadly due to a lack of trained facilitators, frequent and intense coaching sessions may be too time intensive particularly for working families and limited available resources and funding may make it too expensive to run (Dawson-Squibb, Davids, Harrison-Johnson, et al., 2019). The primary goal of PET is to improve child outcomes as well as parent outcomes, since child centred ASD interventions invariably impact on parents. Thus, the parent plays an integral role in contributing to treatment goals and practicing skills outside of the intervention context (Hampton et al., 2019; Kaiser & Hancock, 2003).

Parent education and training programmes focus on increasing parent knowledge about child development and certain conditions, such as ASD and they include active skills training to equip parents with effective parenting skills. These programmes are designed to enhance

competence and confidence in parents, allowing them to raise children in a loving, consistent and predictable home environment (Haslam, Mejia, Sanders, & Vries, 2016). Research suggests that effective PET programmes improve parenting style and are aligned with reductions in child emotional and behavioural problems (Haslam et al., 2016). Additional empirical evidence supports the efficacy of early parent-implemented interventions as essential, particularly with regard to language acquisition (Estes et al., 2019; Hampton & Kaiser, 2016; Yoder & McDuffie, 2006). Furthermore, involving parents in early intervention programmes reduces the necessity for financial and human resources which are scarcely available in low-income settings, and involving parents as intervention agents for children with autism reduces parent frustration and is known to increase parent satisfaction levels (Coleman & Karraker, 1998; Hohlfeld et al., 2018; Williams, Hastings, & Hutchings, 2020).

The early childhood years, defined in this study as 0-5 years of age is in line with international Early Childhood Development Programmes, are a period of rapid physical and psycho-social development for children, therefore making it an important window for early effective intervention (Black et al., 2017; Wittkowski, Dowling, & Smith, 2016). During this period parents play an integral role in shaping their child's physical, emotional and social environment, they have the ability to influence their child's development (Coleman & Karraker, 1998; Wittkowski et al., 2016). Positive attention from parents paired with affection, warmth and responsiveness have been associated with positive child developmental outcomes (Wittkowski et al., 2016). Research suggests that in impoverished communities possessing a strong sense of personal competence can be a crucial buffer against adversity and can act as a protective role to promote the well-being of children growing up in disadvantaged environments (Coleman & Karraker, 1998; Wittkowski et al., 2016). Furthermore, families feel that early childhood intervention (ECI) services have a positive impact on their child's development (Coogle & Hanline, 2016).

Since it has been established that parenting is adaptable to change, a pivotal mechanism for providing early intervention is through parents and promoting effective parenting (Wittkowski et al., 2016; Wyatt Kaminski et al., 2008). Consequently, a number of parenting interventions have been designed and presented globally over the past few decades (Dawson-Squibb, Davids, Harrison-Johnson, et al., 2019; Germansky et al., 2020; Haslam et al., 2016; Oono et al., 2013; Prata, Lawson, Coelho, & Hernâni, 2018).

The majority of these interventions have been designed to improve the parent's ability to successfully parent their child through training, support and education, with the main goal being to enhance the overall knowledge and skills of the parent (Coleman & Karraker, 1998; McConachie & Diggle, 2007; Williams et al., 2020). Researchers have indicated that parental self-efficacy may have an important role to play in the development of the child (Coleman & Karraker, 1998; Williams et al., 2020). As noted by Smetana (1995) efficacious parents work diligently to prevent risks and provide positive experiences for their children, even in the presence of multiple stressors. Numerous personal and psychological factors have been explored to account for the discrepancy in varying levels of parental self-efficacy and satisfaction, these include: parent stress, depression, child care experience and knowledge of development, attitude and belief about parenting, expectations and self-efficacy. According to parental cognitions literature, self-efficacy beliefs provide a powerful variable for parenting skills and satisfaction (Coleman & Karraker, 1998; Smetana, 1995, 2004). Therefore, in brief, individuals with a high sense of perceived self-efficacy (SE) confidently trust their own abilities when faced with environmental stressors and demands, these people tend to perceive problems more as challenges than as threats or events that are beyond their control, they also experience less negative emotions when engaged in difficult tasks and demonstrate perseverance in the face of problematic situations (Coleman & Karraker, 1998). In contrast, individuals with a low sense of self-efficacy tend to experience significant levels of self-doubt and anxiety in the presence of adversity, they assume more responsibility for failure than success, perceive environmental demands as threatening and stressful, avoid challenges and cope in a dysfunctional manner with problems (Coleman & Karraker, 1998). Research largely supports a strong association between parental self-efficacy (PSE) and adaptive parenting skills, such as responsive, stimulating and non-punitive caregiving (Coleman & Karraker, 1998; Smetana, 1995, 2004). Therefore, parenting self-efficacy is a powerful factor in optimising child development. As such parental self-efficacy should strongly be considered in interventions focused on influencing parenting behaviour.

The concept of parental self-efficacy is firmly rooted in Bandura's social-cognitive theory (Bandura, 1969, 2012). According to Coleman and Karraker (1998) "parental self-efficacy beliefs refer to the parent's expectations about the degree to which he or she is able to perform competently and effectively as a parent" (p.58). Parental self-efficacy can also be defined as an individual's beliefs about their capabilities to mobilise the motivation to arrange and carry out tasks or actions to produce a specific achievement in life. Therefore, self-efficacy is

fundamental to conducting behaviour and it influences behaviour change. According to Bandura it is through one's actions that people create environmental conditions that affect their behaviour and this relationship is reciprocal in nature (Bandura, 1969). Therefore, the framework of the social cognitive theory is based on the assumption that we are actively able to influence and shape our environment by mustering the necessary motivation, cognitive resources and courses of action needed, rather than remaining passive reactors to it. It is within this framework that the concept of self-efficacy develops. One's reactions to events in the current environment potentially can alter the strength of their self-efficacy beliefs, this in turn, impacts on future behaviour, therefore creating the opportunity for change to occur. Thus, self-efficacy is one of the most powerful predictors of a person's success as it plays an integral part in the goals a person plans, which activities they engage in and the coping actions he or she will adopt under challenging circumstances (Harty, 2009).

Parental self-efficacy is a sub-component of general self-efficacy and has been broadly explained as the expectation a parent holds about their ability to parent successfully (Coleman & Karraker, 1998; Smetana, 1995). There is considerable evidence showing a strong link between parental self-efficacy and parental competence, higher levels of parental self-efficacy relate to more effective parenting that optimise the developmental outcomes of their children (Coleman & Karraker, 1998; Hohlfeld et al., 2018; Smetana, 1995; Williams et al., 2020; Wittkowski et al., 2016). Consequently, developers of parenting intervention programmes have paid substantial attention to the mechanisms through which PSE beliefs can be improved (Einfeld et al., 2012; Williams et al., 2020). PSE is a good outcome measure to determine whether changes have occurred in self-efficacy after parents have completed PET programmes (Hohlfeld et al., 2018). It is Bandura's (1969) belief that four primary factors influence and contribute toward the growth and development of an individual's self-efficacy beliefs, namely, *personal experience or enactive mastery* (this results from prior accomplishment in specific activities), *vicarious experience* (watching others achieve outcome), *verbal persuasion* from others; and *emotional arousal* experienced in a situation, such as stress, anxiety or fear. These methods serve to either increase or decrease perceived levels of PSE. According to Bandura (1971) self-efficacy beliefs founded on direct (personal) experiences are the strongest of the four factors as they are least vulnerable to change. Therefore, mastery experiences are crucial for the maintenance of self-efficacy beliefs as it is forged from experiencing success in previous situations. As such by allowing parents to experience success in situations which they previously deemed challenging, is crucial to the enhancement of PSE. Vicarious learning

involves parents watching a competent model achieve success in a challenging situation similar to one they might encounter. This method is especially powerful when parents can relate to the model, as it allows them to re-assess their own mastery abilities. Thus, incorporating group discussions with other parents experiencing similar challenges, watching video demonstrations or live parent models successfully implementing activities that are perceived as challenging may increase PSE levels (Hohlfeld et al., 2018). A third factor that may influence the growth of parental self-efficacy beliefs is the use of verbal/social persuasion where others provide informative verbal feedback on the individual's capabilities during a given task. According to Bandura (1997) encouragement from peers is a constructive way to improve self-efficacy and skill. Finally, the fourth way in which self-efficacy beliefs can be influenced is through emotional arousal.

Since self-efficacy beliefs can be enhanced, it is important to examine the three dimensions of efficacy expectations in which change is most likely to occur, namely magnitude, generality and strength (Bandura, 1977). Magnitude denotes the level of self-efficacy and is associated with the level of complexity of a task that an individual believes he or she is able to able to successfully accomplish. Generality is used to describe the quality of self-efficacy that makes it possible for an individual to transfer beliefs of competence garnered under one set of circumstances to other activities that are completely different. Strength of self-efficacy beliefs signifies stability in that weak beliefs may easily be swayed in the presence of negative experiences, as opposed to strong beliefs of competence that will not easily be altered. Bandura (2012) states that self-efficacy beliefs are among the strongest predictors of success and performance in many contexts. This should be of particular relevance and importance to parent training programmes, since increasing skill and knowledge may only lead to changes in behaviour if the parent also has sufficient competence and confidence in their own abilities. Parents with low PSE were found to be unable to put parenting knowledge into practice (Smetana, 1995). Therefore, PET programmes focusing on knowledge and skills alone may not suffice. Wittkowski and colleagues (2016) argue that integrating positive parenting practices that enhance the development of parental self-efficacy, would allow parents to become self-sufficient in creating and maintaining change. Parents of children with ASD report higher levels of stress, anxiety and depression compared to parents of neurotypical children, this can lead to a decrease in PSE levels (Williams et al., 2020). Reduced parental self-efficacy levels and increased mental health challenges can impact adversely on parenting behaviours (Coleman & Karraker, 1998; Williams et al., 2020). Parents who experience increased levels

of stress, anxiety and/or fatigue will find it more challenging to experience success given their physiological arousal levels (Williams et al., 2020). Parental self-efficacy has also been known to mediate and act as a buffer against the impact of adversities in life, such as stress, anxiety and depression (Coleman & Karraker, 1998; Smetana, 1995). Perceived self-efficacy impacts on the amount of effort an individual expends and how long they persevere for in adverse situations. Low self-efficacy can inhibit the acquisition of new skills and supress existing skills (Coleman & Karraker, 1998; Wittkowski et al., 2016). These elevated rates of parental mental health in combination with the frequent behavioural challenges of raising a child with ASD represent a significant need for intervention programmes to include mechanisms to enhance parents' levels of self-efficacy.

Although PSE is proposed as one crucial factor in parent education and training programmes, cultural diversity within South Africa is another to consider. Given the diverse cultural, socio-economic and language climate in South Africa, it is crucial to understand family needs and perspectives within the country, considering its heterogeneous population it would be prudent to not presume that all family needs are the same. Guler et al. (2018) and Mthombeni and Nwoye (2018) assert this factor by providing valuable information regarding the needs and perspectives of black South African families raising a child with autism. Guler et al. (2018) share insights into the needs of South African parents and caregivers raising a young child with autism. The study revealed that parents reported being plagued by numerous concerns such as a lack of social support, misconceptions and a limited knowledge regarding the nature of ASD. Additional challenges after diagnosis included limited availability of intervention services and a lack of practical guidance as well as anxiety about their child's prognosis (Franz et al., 2017; Gona et al., 2016; Guler et al., 2018). Parents of children with autism experience increased personal stress and strain on finances, all of which are highly likely to generate marital conflict. Parents reported feeling unheard and insufficiently informed by treatment providers who in their opinion often were inadequately educated and experienced about ASD. Additionally, parents painted a bleak image of the situation regarding delays in receiving diagnoses and emphasised the shortage of support services and educational facilities for children with ASD (Guler et al., 2018). They noted the dire need for individualised autism specific education and development of programmes and that their children struggled to generalise their communication skills to all settings (Franz et al., 2017; Gona et al., 2016).

Gona and colleagues (2016) conducted a study on Kenyan families living with a young child with autism and identified coping mechanisms which were believed to positively influence parental behaviour. These coping mechanisms included higher socio-economic status, social support, open communication between parents and family members and a positive family ideology. Additionally, they concluded that parents and families needed to feel supported and empowered within their own communities and countries. A manner to achieve this is for professionals to engage and involve parents in their treatment options, particularly to strengthen parental knowledge and enhance communication skills between parents and children with communication delays (Gona et al., 2016).

In their research Mthombeni and Nwoye (2018) indicate that ASD symptoms and treatments are often approached from a Western cultural perspective and yet non-Western cultures, such as the African culture does not perceive ASD as a mental health disorder. Cultural classification of illness in the African traditional system falls into two categories; (1) natural causes of illness and (2) supernatural causes of illness. Illnesses arising from natural causes refer to pathologies such as, diabetes, epilepsy, asthma etc. The notion of super-natural illnesses are used for explaining illnesses that are rare or uncommon, such as ASD (Mthombeni & Nwoye, 2018). Given the diverse South African cultural climate, immense cultural and indigenous understanding of illness and mental illness exists, therefore treatment programmes will need to be culturally sensitive and extend beyond a purely Western approach.

Although only a handful of studies have been conducted in the SA context, these overlooked needs and perspectives of families raising a child with ASD are crucial to inform planning and intervention services. The inclusion of parent perspectives and resilience factors will be of paramount importance in driving national and local autism specific intervention programmes (de Vries, 2016; Franz et al 2017).

### 2.8. Teaching Developmentally Appropriate Communication Strategies within Natural Environments

Developments in earlier diagnosis, the importance of early interventions and the development of specific interventions for young children with ASD has led to the emergence and acknowledgement of a group of empirically supported intervention methods derived from both the principles of behavioural learning and developmental sciences, to best reflect the dual contributions of these fields these approaches are referred to as Naturalistic Developmental Behavioural Interventions (NDBIs). NDBIs occur in natural environments, involve mutual

control between child and interventionist and incorporate a variety of behavioural strategies to teach skills to facilitate language growth and developmentally appropriate pre-requisite skills (Schreibman et al., 2015). Therefore, in NDBIs teaching in naturally occurring environments such as play and routine is strongly emphasised, as opposed to teaching in highly structured environments such as at a table (Tiede & Walton, 2019). Teaching in this manner is achieved by placing substantial emphasis on social learning as a mechanism for language development, while still taking into consideration the need to allow the infant to develop skills across social-communication and other developmental areas. It is crucial that these interventions are implemented in a naturalistic way, with socially and environmentally appropriate naturalistic rewards and reinforcers. Lastly, the foundation of NDBIs lie with using the child's parent or carer as the natural intervention partner (Schreibman et al., 2015).

There are numerous studies demonstrating the effectiveness of NDBIs as an empirically-based intervention for children with developmental disabilities, including autism (Einfeld et al., 2012; Schreibman et al., 2015; Tiede & Walton, 2019). There are several interventions that fall under the NDBI approach, such as: Early Start Denver Model (ESDM), Enhanced Milieu Teaching (EMT), Joint Attention Symbolic Play Engagement and Regulation (JASPER), Stepping Stones Triple P programme, Early Bird (EB) and Early Bird Plus (EBP), Hanen and Social Communication/Emotion Regulation/Transactional Support (SCERTS). These well-known interventions are supported by a broad evidence-base which demonstrate improvement in the following areas; increased use of skills across settings other than use of the skill only in the setting where teaching occurred (generalisation), improved interactive engagement and the use of spontaneous communication, and a decrease in challenging behaviours (Dawson-Squibb, Davids, & Vries, 2019; Einfeld et al., 2012; Franz & Dawson, 2019; Kaiser & Hancock, 2003; Paul, 2011). Research on NDBIs show that children learn best when they are actively engaged in developmentally appropriate learning contexts that are meaningful to the child (Schreibman et al., 2015). Scientific research on development explains that although some children follow an atypical pattern of language development, many children with developmental disabilities follow similar trajectories compared to neurotypical children, albeit at a slower rate (Hampton & Kaiser, 2016).

NDBIs fall under the umbrella of parent-mediated interventions rather than parent psychoeducation and training (Bearss et al., 2015) as parents are coached in a one-to-one format to implement strategies known to enhance engagement, joint attention and social interaction. However recent hybrid PETs, like Hanen's more than words programme (Carter et

al., 2011) ; and teaching social communication to children with Autism (Ingersoll & Dvortcsak, 2010) are beginning to use a blend of home-based sessions (with some parent coaching) together with more didactic group-based sessions. Consequently, PET programmes are beginning to incorporate communication strategies like contingent responding, which have been successfully taught in NDBI's.

### 2.9. Study Rationale

There are very few standardised PET programmes in South Africa that have been published or received systematic programme evaluation of content, outcome and benefit. It is highly unlikely that there will ever be a sufficient number of skilled therapists to work individually on a regular basis with African children who have ASD, therefore initiation and sustainability of early interventions proves a considerable challenge. However, a potential solution to thwart this difficulty is to provide group-based training to the parents of African children. Additionally, group-based parent training formats are more cost-effective than individual interventions as they reach multiple families in a session and provide families with informal social support. An additional advantage of training parents of children with ASD is that it supports the acquisition of skills across a variety of naturalistic contexts, thus encouraging generalisation of skills (Schreibman et al., 2015). Furthermore, the home context is a familiar one to the child and the parent is a familiar communication partner. Training parents to implement specific strategies in a natural context, such as the home also provides the child with access to regular and consistent input and support. Various systematic reviews conducted in SSA have supported parent requests to be engaged in empowerment models and trainings which offer practical strategies that can be used with their children in their homes (Abubakar, de Vries etc 2016). Data presented by Hohlfeld and colleagues (2018) indicates that that parents of children younger than 5 years of age demonstrated the highest increase in PSE levels after completing parenting interventions. However, we know that in SA, families may only receive a diagnosis much later than in HIC contexts. But PET programmes remain a viable option for families of children newly diagnosed with ASD, irrespective of the child's age. While there has been great focus in high income countries on the development and implementation of parent interventions to address challenges, parents encounter with disruptive behaviours, very few interventions programmes are focused on social-communication and speech development. This is surprising considering the staggering percentage (30-50%) indicated by research of autistic children who do not develop sufficient functional speech.

In this study we developed a group-based PET programme and implemented it locally to teach key communication strategies to parents of young children (2.0 to 7.11 years) with autism and enhance parental self-efficacy levels. The goal of Communication Parenting Strategies (COMPAS) is to create hope-filled lives for parents of children with ASD, by providing parents with skills to enhance their abilities to interact with their children in a positive way, and by teaching these skills in such a way that parents increase their belief in their own abilities to parent their children. We hope that data from this PET will extend the growing body of evidence-based ASD interventions that are appropriate and acceptable in LMIC contexts.

### 2.10. Summary

This chapter highlighted the challenges faced by LMIC countries in ASD identification and the provision of evidence based early interventions. The chapter explores the need for ASD intervention which are appropriate and acceptable to parents. It emphasised the importance of enhancing parents' belief in their own abilities to raise and take care of their children throughout life. Furthermore, it provided information about the value parent education and training programmes offer as an entry level evidence-based intervention. The literature offers valuable insights for clinicians who aim to provide parent training in LAMI countries such as South Africa where there remains a dearth of published studies on the effectiveness of parent training programmes.

# Chapter: 3

## Overview of the Research Study Methods

### 3.1. Introduction

This chapter outlines the methodology selected to investigate the above research aim. Firstly, the aims and objectives of the study are presented, followed by a discussion of the research design and phases. Additionally, a description of the participants and participant selection criteria is provided, as well as an overview of the tools used in this study. Lastly, the data collection and data analysis procedures are described. An in-depth discussion of the participants and results pertaining to the different phases will be covered in the subsequent 2 chapters; namely Chapter 4: Development and Stakeholder Views and Chapter 5: Implementation of the COMPAS programme.

### 3.2. Research Question, Aims and Objectives of the Research Study

#### 3.2.1. Main Aims

The main aim of this study is two-fold. Firstly, to design a group-based parent education and training (PET) programme (COMPAS) and determine its appropriateness and acceptability. Secondly, to investigate the clinical effectiveness of the programme to improve the communication interaction skills and self-efficacy beliefs of parents of young children with autism.

#### 3.2.2. Objectives

The following objectives were developed to fulfil the main aim:

1. To develop a group-based (PET) programme focussed on stimulating social-communication and language development.
2. To establish the appropriateness of the parent training programme by engaging with relevant stakeholders.
3. To implement the programme and determine if there is a significant change in pre and post test scores for PCI and PSE to document the effectiveness of the COMPAS programme.

### 3.2.3. Research Hypotheses

1. The COMPAS programme will be acceptable and appropriate to both parents of children with ASD and professionals working with these families.
2. The COMPAS programme will improve interaction skills and parenting self-efficacy levels of parents of young children with ASD.

## 3.3. Research Design and Study Phases

This study follows an exploratory sequential mixed methods research design (Creswell & Clark, 2011). A core premise in mixed methods is that using complementary methods in pursuit of a question yields greater insight than would either method alone or both independently. In this study data collected in phase 1 is used to inform the implementation of the study in phase 2. Data integration occurs by connecting the data from phase 1 with the data from phase 2. The design process for this study was adapted from the Replicating Effective Programs (REP) framework (Kilbourne, Neumann, Pincus, Bauer, & Stall, 2007). Kilbourne et al. (2007) originally used the framework to adapt and implement an existing evidence-based programme in a community setting. The REP framework consists of 4 phases: namely pre-conditions; pre-implementation, implementation and maintenance and evolution. In the pre-considerations phase, researchers identify the need, target populations and suitable intervention. In the pre-implementation phase the focus is on adapting the intervention with input from community stakeholders. Implementation and evaluation of the training occurs in the implementation phase and in the maintenance and evolution phase the focus is on identifying factors that affect the sustainability of the intervention. According to Kilbourne et al. (2007), REP is a promising approach to implement effective interventions that involve complex behavioural components such as group-based education and training.

In this study we have adapted the original focus of the REP framework and used the phases to plan, develop and implement a *new* programme developed in the South African context, namely the Communication Parenting Strategies (COMPAS) training programme. This research study followed a sequential process that involved the first three phases of the REP framework namely: the pre-conditions, or development phase; the pre-implementation phase (or stakeholder input phase) and the implementation phase. The objectives and processes of each

phase, as well as the number of participants and data collection tools employed, are represented in Table 1.

Table 1. *Research Objectives, Participants, Processes and Data Collection Tools (adapted from (Kilbourne et al., 2007)*

| Phases | Objectives | Participants | Process | Tools |
|---|---|---|---|---|
| **Phase 1: Pre-conditions** | | | | |
| **<u>Phase 1</u> Pre-conditions: COMPAS development** | Identify communication strategies<br>Identify teaching materials and activities | None | The content of the COMPAS parent training programme was developed by reviewing the literature related to parent/caregiver education and training programmes and self-efficacy studies.<br>This process informed the selection of the 4 key communication teaching strategies as well as the teaching activities included in the programme | Teaching materials<br>The following materials were developed during this phase:<br>• Facilitator PowerPoint Presentation<br>• Videos of expert parents modelling teaching strategies<br>• Toy set used during video modelling of parents with their child |
| **Phase 2: Pre-implementation (stakeholder feedback)** | | | | |
| **<u>Phase 2</u> Pre-implementation: determining appropriateness and acceptability** | Determine the acceptability and appropriateness of the COMPAS programme | Parents (n=25) who have a young child with ASD<br>Professionals (n=5) with five or more years working with children with ASD and their families | 1. The content of the training programme and manual was sent to a panel of subject matter experts (n=5) for their appraisal regarding appropriateness of the programme<br>2. The acceptability of the training programme was tested during a pilot testing with parents (n=25) with young children with ASD | **Custom-designed feedback questionnaires**:<br>• Professional Appropriateness Evaluation Tool<br>• Parent Acceptability Evaluation Tool<br>• Demographic questionnaire<br>**COMPAS parent Manual**<br>**Vocabulary Lists for Toy Sets** |
| **Phase 3: Implementation** | | | | |
| **<u>Phase 3</u> Implementation: clinical** | Establish the effectiveness of the group parent training | Parents (n=31) who have a young child with ASD | **Parent Training**<br>The group parent training was run in two formats | **Baseline Measures of Child Characteristics** |

| | | | |
|---|---|---|---|
| **effectiveness of COMPAS** | programme on parent-child communication interaction (PCI) and parent self-efficacy (PSE) | 1. Three Saturday morning sessions (n=22)<br>2. One full day training which occurred on a Saturday (n=9)<br>Parents (n=31) self-selected which format to attend based on their availability | • Preschool Language Scales (PLS-5th edition)<br>• Eyberg Child Behaviour inventory (ECBI)<br>**Pre and Post Tools**<br><u>Parenting Interaction</u><br>• Parenting Interactions with Children: Checklist of Observations Linked to Outcomes (PICCOLO)<br><u>Parenting Self-Efficacy</u><br>• Parenting Sense of Competence (PSOC)<br>• Parenting Self Efficacy Measuring Instrument (PSEMI) |

In the first *preconditions phase*, we developed the content of the COMPAS parent training programme. This phase involved reviewing both parent-implemented interventions and self-efficacy literature in order to determine programme content namely; identification of social-communication strategies and teaching activities that would be optimal for mastery of parent interaction skills and enhancement of parental self-efficacy. Some of the specific essential teaching materials were developed during this phase. These included, the PowerPoint presentation employed by the training facilitator, instructional videos of the expert parents modelling the teaching strategies with their children; and a toy set to facilitate play and communication interaction between parents and their child during the baseline testing. The same toy set was used during the COMPAS role play activities.

During the second *pre-implementation phase*, we sought stakeholder views on the acceptability and appropriateness of the programme content using a descriptive design. The sampling method used for phase 2 was non-probability, purposive sampling (Etikan, 2016). Non-probability sampling is a sampling method where participants are chosen deliberately based on the qualities the participant possesses. We used expert sampling (Etikan, 2016), 2016) as we wished to determine whether stakeholders felt that the programme had value and would be

worth implementing. Additionally, we developed the accompanying training manual (full copy available on request) and created a list of words targeting specific vocabulary (nouns, adjectives, pronouns etc) for each toy set, which could be used as a guide for the participants during teaching activities.

Three key activities took place in phase 2:

- The content of training programme and accompanying training manual was sent to a panel of subject matter experts (n=5) for their appraisal.
- The acceptability of the COMPAS training programme was tested during a pilot study on a single group of parents (n=25) with young children with ASD who presented with minimal to no verbal communication.
- The content of the parent training programme and manual were refined based on the recommendations obtained from the panel of professionals and group of parents.

We established the effectiveness of the group parent training on parent-child interaction (PCI) and parental self-efficacy (PSE) in the third *implementation phase*. Phase 3 uses a pretest-posttest single group design (McMillan & Schumacher, 2001). The pre and post-test single group design is frequently used for testing hypotheses about the effects of intervention in clinical educational research. The pretest-posttest group design has value to clinicians and practitioners as it is uncomplicated to conceive and implement allowing clinicians to conduct research in their clinical environment (Rausch, Maxwell, & Kelley, 2003). In the pretest-posttest group design the dependent variables (e.g. parent-child interaction skills and parent self-efficacy) are measured on two different occasions, once prior to the commencement of the training and once after the completion of the training. The sampling method used for phase 3 was convenience sampling (Etikan, 2016). There were conceptual and functional purposes for choosing convenience sampling technique. The consolidated waiting list for ASD formed the sampling frame for the study since the researcher had access to the waiting list. We deliberately recruited, families who were at the bottom of the waiting list at the time of the study as these families would wait the longest time for educational/intervention services. Thus, parents were recruited to the study because they were likely to be interested in participating in a PET programme and would potentially benefit from the programme.

Four key activities occurred in phase 3:

- Conducting baseline testing for all the children with ASD whose parents consented to participate in the study.
- Implementing the training programme to the parents. The first group (n= 22) received the training over 3 Saturday morning sessions (12 hours) and the second group (n=9 received the training over one full day on a Saturday (10 hours) due to work commitments and other time constraints.
- Administering the outcomes measures before and after implementing the training programme.
- Analysing the data from the baseline as well as the outcomes measures.

### 3.4. Participants

In phase 2, two separate stakeholder groups appraised the parent training programme to determine its appropriateness and acceptability in a South African context. In order to determine appropriateness a panel of subject matter experts evaluated the training programme. In order to be included in the expert panel, health care professionals needed to have worked within the field of ASD for 5 years or more. We set out to target typical members of the multi-disciplinary team for children with ASD namely psychologist's, speech and language therapists, and occupational therapists. A second panel, consisting of parents of children with ASD, rated the programme's acceptability, after completing the COMPAS programme pilot study. Parent participants in this phase were recruited using convenience sampling from within the professional networks available to the researchers. These parents met the same criteria as the parents in phase 3 (see below).

In phase 3, the parents were invited to participate if they met the following inclusion criteria:

- The parent has a child with autism between the age of 2.0 and 7.11 years of age who is currently placed on the Western Cape Education Department's Consolidated ASD waiting list.
- The parent's level of proficiency in English should be such that they are able to speak, read and write basic English as the training programme was delivered in English.

- The parents were required to indicate their availability to attend the training programme, which occurred on Saturdays. Due to a limited capacity at the training venue only one parent per household (either the mother or father) was required to attend the intervention programme. The same parent was required to complete the training programme from start to end as this was to ensure consistency and continuity of information and skills acquired.
- The parent should be the primary caregiver of the child.

Children with ASD are considered secondary participants in phase 3 since they were not be involved in the training programme but were part of the pre and post-test measures. Consequently, the children needed to meet the following criteria as reported by their parents and determined by assessments conducted during pre-testing.

- The children should have an established diagnosis of Autism Spectrum Disorder (ASD) by a psychologist or medical doctor as confirmed by the parent.
- The children should be between the ages of 2.0 and 7.11 years of age.
- The children should be low-rate communicators.
- The children should be able to follow basic single instructions as reported by the caregiver.
- The children should be intentional communicators (i.e. should use some basic gestures) as reported by the parent.
- The children should receive less than 4 hours of therapeutic intervention a month.

### 3.5. Research Personnel

Research personnel for the study consisted of a primary facilitator (researcher) and 2 qualified speech and language therapists (SLTs), experienced in working with children with ASD who acted as co-facilitators during the training. In order for an individual to qualify as a research assistant in this study, they required a professional SLT qualification and a minimum of two years' experience in the field of ASD. The duties of the facilitators included, facilitation during group task sessions and completion of the procedural integrity checklist to ensure that each training session was presented consistently. Additionally, 5 'expert' parents were recruited as co-facilitators. The 'expert' parents all have a child with autism who have received long-term speech and language therapeutic intervention and because their children had received extensive

speech and language intervention, they were familiar with the four communication strategies taught in the training programme. The expert parents were involved in the development of the instructional videos in which they were filmed demonstrating the strategies with their own children. They participated in a panel discussion in which they shared their journey from diagnosis until the present. This occurred during the first COMPAS session. In the subsequent sessions they acted as co-facilitators with the two speech and language professionals. Additionally, the ECBI scores were checked by a clinical psychologist, who had a minimum of 5 years of experience working with children with ASD.

### 3.6. Data Collection Procedures and Ethical Considerations

Approval for the study was granted by the University of Cape Town's Ethics Committee (Faculty of Health Sciences) (242/2016) as well as the Western Cape Education Department (WCED), and can be viewed in Appendix 1 and 2. Data collection followed the ethical guidelines stipulated by the Declaration of Helsinki (World Medical Association, 2012).

Once permission was obtained from the WCED, contact was initiated with parents on the centralised ASD data base who were presumed to fit the selection criteria. The researcher followed a script to provide parents with essential information regarding the study such as, participant selection criteria, implications on parent's time and resources. This salient information was also provided in a formal letter and emailed to parents immediately after telephonic contact had been made with them. Once the parents indicated that they were interested in participating in the training programme, the researcher then established an initial appointment with the potential participants via email or telephonically.

Written consent was obtained at the initial meeting. In the cover letter accompanying the consent form, parents were informed of the procedures for data collection. Their attention was drawn to the fact that they could withdraw at any stage of the study without any negative implications for their child. The detailed information related to the study were outlined in an information sheet which was given to the parents to keep as a reference. Parents who consented to participate in the study provided consent in writing by signing a tear-off slip which the researcher kept (see Appendix 3).

Consenting parents began their pre-testing at the initial consultation with the researcher. Parent-child interaction was coded using the PICCOLO during the initial 7-minute video recorded play session between each parent and child dyad. The PLS-5 was administered on each child

to establish baseline communication and language scores. Pretesting was completed with all families over a 3-month period.

At the conclusion of the pretesting, parents were allocated to one of two groups depending on parent availability and work commitments. Parents self-selected to attend a morning only group (which ran over 3 Saturdays) or a full day training (which occurred over one full Saturday). Parent group allocation was confirmed via email and telephonically. After each training session parents were given an allowance of R25.00 which contributed towards the cost of transport to the venue.

At the beginning of the first COMPAS training session parents were issued with questionnaires to complete. These questionnaires consisted of the custom designed demographics questionnaire, PSOC, PSEMI and ECBI. Once the questionnaires were completed, they were collected by the facilitators and the training then commenced (see training programme outline in Appendix 4). Directly after the last training session parents completed the two parent report post-test measures, namely the PSOC and PSEMI. Parents returned to the testing site for the PCI measure (PICCOLO) to be administered, this post-test measure was conducted within one month of completing the training. In order to ensure confidentiality all documentation gathered during the study was de-identified and participants were assigned a participant number which allowed researchers to collate the biographical information with the baseline and outcome measures.

### 3.7. Data Collection Materials

We used a combination of direct observation tools and parent report measures in the study (see Figure 1). All of the tools described below have been used in previous studies with families of children with autism.

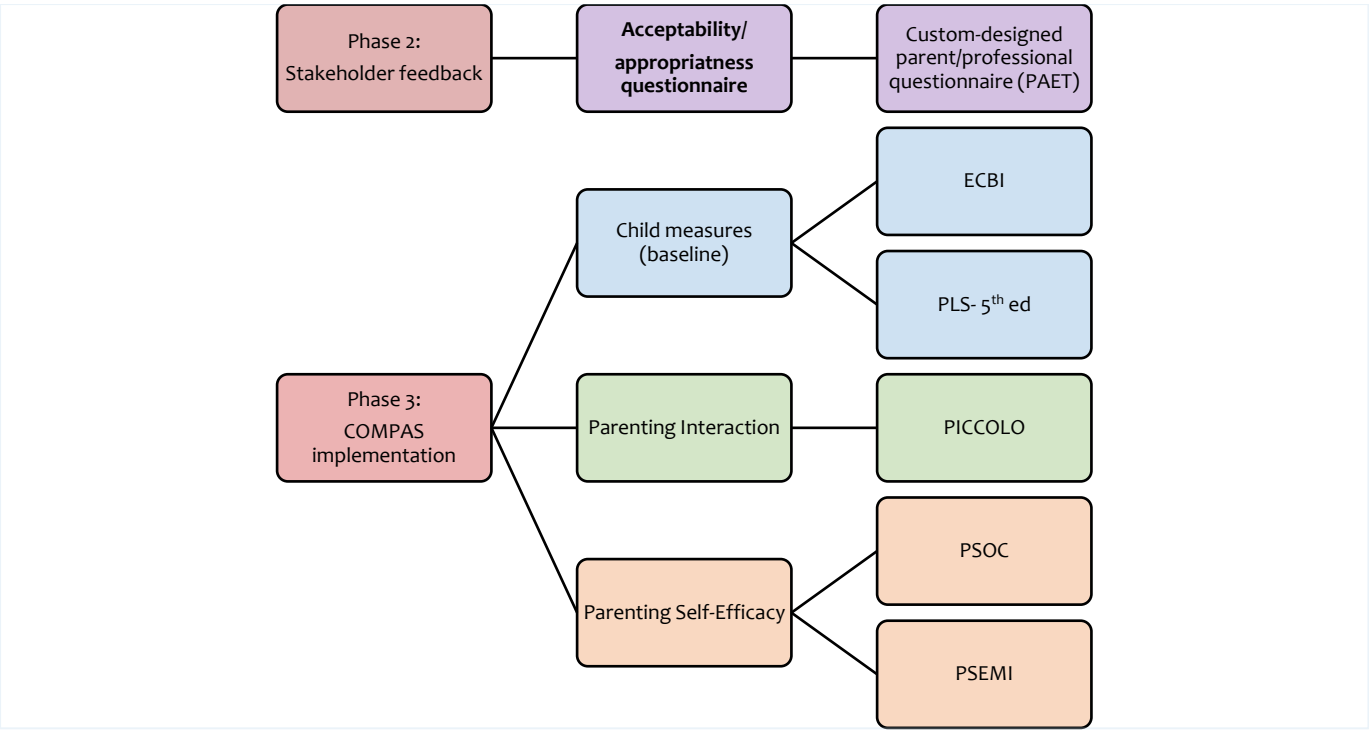


*Figure 1.* Research phases and corresponding data collection tools

### 3.7.1. Acceptability Questionnaires

#### 3.7.1.1. Professional Appropriateness Evaluation Tool (PAET: Professional)

A custom-designed, 4-point Likert scale questionnaire was developed for the experts to evaluate the training programme on the following four elements: *relevance* of content, *comprehensiveness* of content, *relevance* of teaching activities and *relevance* of teaching materials. The response format presented to the subject matter experts ranged from 1 (*"Not relevant/comprehensive"*) to 4 (*"Very relevant/comprehensive"*). The researchers asked the experts to provide written comments relating to the appropriateness of the training package, as well as to make recommendations for improvement on any aspect of the programme they reviewed. The questionnaire can be viewed in Appendix 6.

#### 3.7.1.2. Parent Acceptability Evaluation Tool: (PAET: Parent)

A custom-designed questionnaire was used in this study to capture parents' perspectives on the acceptability of programme goals, content and procedures as well as programme outcomes. The 18-item questionnaire consisted of 3 sections namely *acceptability of the programme goals, content and procedures, as well as communication outcomes.* The response format was a 6-point Likert scale ranged from 1 (*"Strongly disagree"*) to 6 (*"Strongly agree"*). Parents

were asked to critically analyse the content and structure of the training programme, as well as rate their satisfaction with the usefulness of the communication strategies taught, as well as the appropriateness of implementing one or more of these strategies with their child at home. Additionally, parents were requested to identify any aspects relating to parenting competence which they felt was not included in the training, but that they deemed would be relevant to include. Lastly, parents were required to list any challenges that would prevent them from trying the strategies at home with their child. The questionnaire can be viewed in Appendix 7.

### 3.7.2. Direct Observation Tools

#### 3.7.2.1. PLS- 5 (fifth edition) (Zimmerman, Steiner, & Pond, 2011)

The Preschool Language Scale was used to assess the secondary participants' (children) current receptive and expressive language performance. The PLS is comprised of two subscales: *Auditory Comprehension* and *Expressive Communication*. This standardised assessment tool was designed to identify young children (ages birth to 7.11 years) who present with language delays or disorders. The PLS can be used to assess children who are non-verbal or who have a low language ability. The administration time varies from 20 to 45 minutes. The test allows for the observation of naturally occurring behaviours in younger children. According to test developers, reliability of the PLS-5 was obtained by examining the test-retest stability and internal consistency methods (Zimmerman et al., 2011). The average corrected stability coefficients on the Auditory Comprehension, Expressive Language, and Total Language Scale range from .86 to .95 which indicates good to excellent reliability. For internal consistency, split-half reliability coefficients averaged by age range for Auditory Comprehension, Expressive Communication and Total Language were found to be .90, .93, and .93 respectively (Zimmerman et al., 2011). In this study the PLS was used to determine child language ability at the start of intervention (child baseline characteristic).

#### 3.7.2.2. PICOLLO (Anderson, Roggman, Innocenti, & Cook, 2013)

The Parenting Interactions with Children: Checklist of Observations Linked to Outcomes (PICCOLO) is a standardised observational instrument designed to measure parent interaction and behaviours that are likely to support child development (Anderson et al., 2013). This tool consists of 29 items representing four domains of positive parent interactions: *affection*, *responsiveness*, *encouragement* and *teaching*. During a recorded seven-minute parent-child interactive play session, each item is rated on the checklist by the observer as either *absent* (no

behaviour observed), *barely* (brief or emerging behaviour) or *clearly* (definite, clear signs of the behaviour) (Norman & Christiansen, 2013). This tool has been found to be a psychometrically strong observational measure of early parent-child interaction (Anderson et al., 2013). Innocenti, Roggman, & Cook (2013) found that the PICCOLO demonstrated strong reliability and both construct and predictive validity. The PICCOLO has shown promise as an effective tool for clinicians working with parents who have a child with a disability (Innocenti et al., 2013; Roggman, Cook, Innocenti, Jump Norman, & Christiansen, 2013). In this study this tool was used as an outcome measure for parent-child interaction.

### 3.7.3. Parent Report Measures

#### 3.7.3.1. Demographic Questionnaire

A custom-designed demographic questionnaire consisting of 19 questions was developed to collect key biographical information from the participants such as parent's age, gender, home language, highest level of education completed, age of child at the time of diagnosis and whether or not the child had access to any intervention at the time of the study. The demographic questionnaire can be viewed in Appendix 8.

#### 3.7.3.2. PSOC (Gibaud-Wattston & Wandersman, 1978)

The Parenting Sense of Competence Scale (PSOC) is a domain general tool and is considered the most commonly used tool for measuring parental self-efficacy (Gilmore & Cuskelly, 2009). It is a self-administered questionnaire containing 17 items in which parents indicate their *confidence and satisfaction* in executing their parenting role. The PSOC measures two subscales; efficacy and satisfaction. Efficacy items relate to how confident a parent feels in their parenting abilities, while items on the satisfaction subscale relate to the sense of accomplishment that accompanies the parenting role. The PSOC uses a 6-point Likert format for responses ranging from *strongly agree* (1) *to strongly disagree* (6). Gilmore & Cuskelly (2009) investigating the use of the PSOC with both mothers and fathers involved in the parenting role and demonstrated acceptable Cronbach's Alpha values for each subscale (efficacy: mothers= 0.68; fathers=0.74; satisfaction: mothers= 0.72; fathers=0.76). In this study this tool was used as an outcome measure for parenting self-efficacy.

#### 3.7.3.3. PSEMI (Harty, 2009)

The Parenting Self Efficacy Measuring Instrument (P-SEMI) is a task-specific tool that is designed to measure parent self-efficacy in the following parenting domains: *showing affection and empathy, engaging in play, facilitating routines, establishing discipline strategies, providing appropriate learning and development activities, and promoting communication interaction* (Harty, 2009). The P-SEMI is a self-administered questionnaire consisting of 43 items related to parenting using a 6-point Likert-scale format for responses ranging from *always* (1) to *never* (6). Cronbach's Alpha values for the scale ranged from 0.8 to 0.9 (Harty, 2009).

#### 3.7.3.4. ECBI (Eyberg & Pincus, 1999)

The Eyberg Child Behaviour inventory (ECBI) (Eyberg & Pincus, 1999) is a 36-item parent report measure that documents both the *frequency* and *intensity* of problem behaviours in children between the ages of 2-16 years. Parents are asked to rate the frequency of a series of behaviours on a 7-point Likert scale, where responses range from never (1) to always (7). These scores are summed to create an intensity score. Jeter, Zlomke, Shawler, & Sullivan, (2017) conducted a comprehensive psychometric analysis of the ECBI in children with ASD and reported the tool to have excellent reliability with Cronbach alpha value of 0.92 for the ECBI intensity subscale and a Cronbach alpha value 0.88 for the ECBI problem scale. In this study the ECBI was used to determine parent perception of challenging behaviour (child baseline characteristic).

### 3.8. Training Materials and Equipment

The following materials and equipment were used during the COMPAS training sessions.

#### 3.8.1. COMPAS Parent Manual

A printed 25-page manual was designed to be distributed to each participant. The manual provided an outline of training content, as well as a comprehensive explanation of each of the core communication strategies. Each strategy included accompanying photographs; a reflective activity related to the strategy; steps to ensure the parent can implement the strategy successfully, guidelines on how to implement the strategy at home; as well as a section to document successes and challenges when using the strategy at home.

### 3.8.2. Instructional PowerPoint and Videos

Each of the 4 COMPAS sessions has an accompanying PowerPoint presentation which mirrors the content provided in the parent manual.

### 3.8.3. Toy Sets

Eight toy sets supporting early childhood development and encouraging parent-child interaction were carefully assembled by the researchers into a study toy set. Each of the 8 toy sets contained objects that are developmentally appropriate for children between the ages of 2 and 8 years. For instance, the 'fruit cooking set' contained plastic objects like different fruit, pots, pans, knives, spoons, plates and a puppet for pretend feeding to encourage imaginary play for children at that developmental stage of play. Other toy sets included the 'playdough and cookie cutter' set (which comprised a smaller selection of functional items like playdough, a plastic knife and cookie cutters), and a 'tractor and farm animals/blocks' set (which consisted of plastic tractors, various miniature farm animals, 2 farmers and plastic blocks). All toys were locally sourced and easy to find, the toys consisted of common items that would likely be found in most educational centres and therefore most children would be familiar with them.

Each set contains carefully selected items that encourages engagement and facilitates reciprocal interaction between adult and child. Some of the toy sets extend the child's play by offering different levels at which the child can engage with the toys, e.g. moving from functional play to pretend play. Toy sets (such as the fruit cooking set which included a puppet to feed) were put together to allow room for flexibility in the way a child engages with the toys, i.e. sets evolve as the child's abilities and interests expands. In addition, the sets also come with an accompanying vocabulary list which help parents to introduce a range of new vocabulary items (nouns, adjectives, simple phrases, prepositions, pronouns, negatives and request words) while engaging in play with the child. An image of an example toy set together with a sample of the accompanying vocabulary list may be viewed in Appendix 9.

### 3.8.4 Procedural Integrity Checklist

The procedural integrity checklist is a one-page, operational checklist for the key points relating to consistent session delivery by the facilitator (researcher). The checklist was completed during each session by a facilitator (speech and language therapist) to ensure that the important aspects of the training have been included and not overlooked (e.g. greeting and

welcoming participants, explaining the outcome of each session and introducing new skills, introducing the expert parents and facilitating role play and group discussions). The checklist is included in Appendix 10.

### 3.8.5. Computer Equipment

A laptop and data projector and speakers were used to project the PowerPoint presentation and videos during training.

## 3.9. Data Analysis

All data from the phase 2 acceptability and appropriateness questionnaires were analysed using descriptive statistics, specifically frequency counts and percentages. Relevant quotations from participants were used to support the numerical data. Recommendations from the participants were documented and used to refine COMPAS training materials, activities and procedures. This revised COMPAS programme was then implemented in Phase 3 to determine its effectiveness to change parenting interactions and parenting self-efficacy.

All data from Phase 3 was analysed using SPSS version 25. The reliability (internal consistency) of each measure was determined by Cronbach's alpha. Changes between the pre- and post-intervention scores for the 3 outcome measures were analysed using dependent sample t-tests. Following this, a reliable change percentage was calculated for each of the 3 outcomes measures. Reliable change indicates what percentage of participants showed a marked improvement after intervention that is likely to be clinically meaningful (Evans, Margison, & Barkham, 1998). The formula we used for determining reliable change (Evans et al., 1998) is:

$$(M_1-M_2)/SE_{diff} = SD_1\sqrt{2}\sqrt{1-r}$$

where $M_1$ is the mean score at baseline and $M_2$ is the mean score after the intervention, $SD_1$ is the standard deviation of the baseline observation and r is the reliability of the measure (using Cronbach's alpha). Finally, a linear regression analysis was conducted to determine whether key pre-intervention variables predicted improvement in parent child interaction or self-efficacy post-intervention.

### 3.10. Summary

This chapter presented an overview of the study's research methods. A description of the research question, objectives and hypotheses was provided. Characteristics of each phase of the study was outlined and characteristics of the research personnel and participants were described. Data collection tools were listed and information about their reliability and validity was provided. Data collection procedures were delineated and training materials and equipment related to the study were described. The methods and statistical procedures for data analysis were outlined.

# Chapter: 4

# Development and Stakeholder Views

## 4.1. Introduction

This chapter discusses the development of the COMPAS programme as phase 1. The chapter introduces the 4 key communication strategies taught in the COMPAS programme, as well as the theoretical underpinnings of these strategies. The chapter then proceeds to outline the process that was followed to ascertain stakeholder views and appropriateness and acceptability of the programme (phase 2). Both health care professionals as well as parents were invited to participate in phase 2 of the study. The results from the parent and professional panels are presented and discussed. Finally, recommendations from both panels are presented.

## 4.2. Selection of Social-Communication Strategies to include in the COMPAS Programme

COMPAS is a parent education and training (PET) programme (Dawson-Squibb, Davids, Harrison-Johnson, et al., 2019). As discussed in Chapter 2, there is a substantial body of evidence documenting the positive effects of group-based parent training in high-income countries. However, there is a paucity of published research that has been conducted in low and middle income (LMIC) countries like South Africa to investigate its benefits as a feasible way of providing early intervention to parents of children with disabilities (De Vries, 2016; Tomlinson et al., 2014; Ward & Wessels, 2013). Very few group-based intervention programmes teach skills in assist parents in supporting communication, socialisation and play (Bearss et al., 2015; Koegel et al., 1996; Todd et al., 2010). Current parent-implemented interventions tend to lean towards a general intervention approach without consideration of the child's language level and social abilities. Furthermore, research on parent-implemented interventions has typically documented changes in parent behaviour such as stress in isolation, rather than as a crucial part of the environmental system that supports the child's communication and language development (McConachie & Diggle, 2007). In reviewing the literature, it became evident that contingent adult responding plays a crucial role in reinforcing and increasing the frequency with which the child communicates (Hancock & Kaiser, 2012; Kaiser & Gray, 1993). For this reason, the focus of this parent education and training programme was to teach parents core strategies that they can use to enhance their child's communication abilities.

Thus, the core communication strategies incorporated in the parent training programme were derived from existing parent mediated or parent coaching interventions spanning across the last two decades. In this body of literature, the role of the parent or primary caregiver as a responsive interaction partner in the child's language-learning environment is a complex one, but it can generally be distilled into 4 key components. According to (Kaiser & Gray, 1993) the parent needs to stimulate social interaction and facilitate specific language teaching and learning in the natural environment of the child. This occurs by the *caregiver modelling* general and specific stimuli (models, time delay) during daily ongoing events and social interactions that signals to the child when to talk and what to say. Additionally, the caregiver *mediates the physical and social environment*, he or she *provides broad contingencies* by being generally positive and responsive to the behaviour of the child, when children respond to these prompts they are *reinforced by the consequential adult behaviour* that is contingent on their communication. The four strategies selected for inclusion in the COMPAS programme are:

- Environmental Arrangement
- Responsive Interaction (also known as contingent responding)
- Language Modelling and Expansion
- Milieu Teaching Strategies (also known as incidental teaching)

These strategies are present in many parent coaching programmes that target social interaction skills of children with disabilities. However, for the description of these strategies (below) we rely heavily on the terminology used in the Enhanced Milieu Teaching (EMT) approach (Kaiser & Gray, 1993; Roberts & Kaiser, 2015).

### 4.3. Definition of the Four Core Social-Communication Strategies

The four components of the COMPAS training programme are taught to parents sequentially, with Environmental Arrangement taught first, followed by Responsive Interaction strategies, Modelling and Expansion of language, and lastly Incidental Teaching strategies (i.e. 'Creating Opportunities to Talk'). Each of these four components are discussed below.

#### 4.3.1. Environmental Arrangement

The purpose of Environmental Arrangement is to increase the child's interaction with the physical setting and communication partner by teaching parents to select toys and activities that are of moderate to high interest to the child. When children are interested in the activities

they are presented with, they are generally more motivated to engage with adults in communication interactions for longer periods of time. Choosing activities of interest also creates more frequent opportunities for the parent to communicate with the child. This is further established by teaching the parent to 'set up' the environment and *arrange* materials in a way that will make it easy for the child to know how to play with the toy and facilitate engagement with the parent. For example; building 2 or 3 pieces of a train track, placing a train on top of the tracks and then laying out the remaining pieces of the train track, provide visual clues to the child about what he could do next. This strategy helps the child to initiate play actions that promotes child engagement with the toy and allows the adult to follow the child's lead. Lastly, parents are taught to manage the toys by presenting parts of the toy set sequentially, so that child engagement in shared play can be extended and there are more functional reasons for the child to communicate (e.g. bringing out people or animals who fit into the train carriages, or a stop and go sign for the train track). Therefore, these teaching aspects of environmental arrangement serves the purpose of building and extending play routines as a context for extending the child's engagement in the activity. This basic strategy sets the scene for the remaining strategies (responsive interaction, incidental teaching and modelling and expansion) that extend the principles learnt in this component. This strategy, although largely non-verbal, provides a platform of play actions and creates a basis for communication interaction (Hancock & Kaiser, 2006; Kaiser & Roberts, 2013).

### 4.3.2. Responsive Interaction (Contingent Responding)

The Responsive Interaction component sets a social context for language learning the same way the component of Environmental Arrangement sets a physical context. Together, Responsive Interaction and Environmental Arrangement promote a supportive, interactional setting for social-communication teaching and learning to take place. Core strategies in the Responsive Interaction component include; allowing the child to initiate play and communication, following the child's lead during play and conversation, imitating otherwise known as 'mirroring' the child's actions while providing verbal descriptors, and verbal and nonverbal turn-taking. When the child performs an appropriate action or play behaviour the adult responds contingently by being largely positive and responsive to the behaviour of the child, this reinforces and increases the frequency of the child's communication. The purpose of this effective language learning strategy is to engage the child and parent in nonverbal and verbal interactions which provide opportunities for the adult to model new language forms and

vocabulary. Following the child's lead and 'mirroring' the child's actions builds a non-verbal connection between the child and adult, particularly in the case of children who have minimal language or who are nonverbal. This further increases the likelihood that the child will engage with the parent as a conversational partner. Additionally, these strategies allow the parent to mediate the physical and social environment for the child and as a result facilitate linking the child's communication to the environment (Hancock & Kaiser, 2006).

### 4.3.3. Modelling and Expansion (of Language)

Language modelling may be regarded in the literature as one of the most important teaching strategies (Kaiser & Hancock, 2003). This is when the adult first establishes joint attention by focusing their attention on the child and the child's current interest or activity. Thereafter, the adult provides the child with a salient, specific *verbal model* of targeted language that is appropriate to the child's interests and developmental level and is contingent on what is happening in the activity. It is crucial for parents to model diverse vocabulary (i.e. nouns, verbs, adjectives, pronouns, conjunctions and negation words) particularly to the child with autism who may have restricted interests and therefore make it difficult to do so. Therefore, adding accompanying toys to the child's restrictive interest may provide adults with additional opportunities to model more diverse vocabulary. For example, should the child present with a narrow interest in playing with sand, adding a bucket and a scoop to the play routine may offer the adult more opportunities to model various language forms, making it easier to expose the child to a range of targeted vocabulary. If the child imitates the adult's verbal model they are provided with immediate positive feedback, this includes an *expansion* of the child's response (adding on *one more word* to the child's response) and receiving the material of interest. An example of language modelling may for instance be when an adult and child are pushing a toy car into a garage, the child may say: *"Car goes"* during play, the adult would respond by saying *"The car goes in"* therefore the adult is *commenting* on the action of the car which can be seen by the child during play. The more opportunities the child has to imitate the verbal model of the adult, the easier it becomes for him to comment on his future actions spontaneously. Furthermore, matching language to correspond with actions is a powerful strategy used to support children who are learning to comment on their own actions (Hancock & Kaiser, 2006, 2013).

### 4.3.4. Creating Opportunities to Talk (Incidental Language Teaching)

Children with ASD frequently have narrow and interests in toys and play routines, these limited interests are often perseverative in nature, which can limit opportunities for modelling and prompting various language forms. Therefore, a careful balance should be struck between providing a toy with which the child will play with for an extended period of time and slowly, but purposefully interrupting a familiar play or everyday routine so the adult can elicit requesting and commenting behaviours as well as model new vocabulary. In Milieu Teaching, as the name suggests, the purposeful arrangement of toys in the environment during a familiar routine create an opportunity for the adult to encourage requesting or commenting from the child. There are many milieu teaching techniques or strategies, but in COMPAS we selected 3 specific strategies to teach parents, *namely offering a choice; missing item from a task and brief turns (or portions).* In the *offering a choice* strategy the adult may give the child a choice of two objects or items. This may be achieved through non-verbal choice requesting, holding up two items for the child to choose within a familiar activity so the child can reach (request) the item he wants. Or the adult might offer choice verbally "do you want the bat or the ball?" in order to elicit a verbal response from the child at whatever level possible should they have speech. Once the child understands the concept of requesting a choice, the range of items offered during choice may be slowly extended. In the *missing item from a task* strategy a visible but out of reach essential item to a familiar routine task that is interesting for the child is displayed, so that the child is motivated to request the item from the adult. For example, during a threading activity the adult may offer the child a few beads to thread, once the child is engaged and familiar with the task and its associated items, the adult may then place the rest of the beads in a transparent jar that only the adult can open. This is so that the child must request each remaining bead from the adult, by reaching, grabbing or pointing. Additionally, this technique also encourages the child to interact with the adult by requesting help to open the closed jar, in order to complete the activity. In the *brief turns/portions* strategy a turn in familiar routine is too short or too brief. By disrupting a familiar routine, the adult may encourage requesting or commenting from the child. An example of a brief portion may include a familiar everyday routine such as a mealtime. In this scenario, the adult provides the child their usual food during a typical mealtime, but instead of placing the complete meal in front of the child, the adult divides the meal into small portions that are out of reach, but in sight to the child. The adult waits for the child to initiate by requesting more food or commenting on what they see, at whatever level possible. It is important for the adult to try these techniques when the child is

calm and not anxious. Disrupting a familiar routine can be anxiety provoking for children with ASD, therefore the adult will need to discern when it is appropriate to incorporate these strategies during a child's familiar routine (Hancock & Kaiser, 2012).

### 4.4. Description of Teaching Activities and Strategies in the Parent Training Programme

The COMPAS training programme was designed to include a variety of activities which have been shown to modify self-efficacy beliefs (Wyatt Kaminski, Valle, Filene, Boyle., 2008). These included didactic PowerPoint presentation; practise in small group discussions; video modelling by an expert parent within a pre-identified routine (e.g. bathing, dressing); expert parent panel discussion; role play opportunities and homework activities (see Figure 2). A sample session of the training programme can be viewed in Appendix 5.

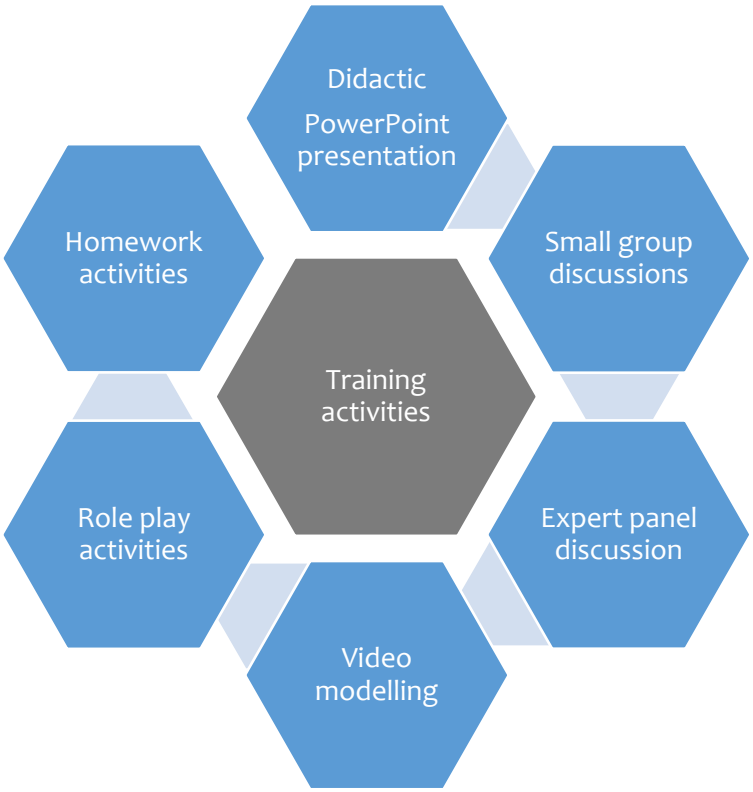


*Figure 2.* Training activities included in COMPAS programme

As seen in Table 1 in chapter 3 at the end of phase 1 the COMPAS programme consisted of a didactic PowerPoint presentation, accompanying instructional videos, as well as a toy kit which

contained 8 toy sets for use during the interactive group-based sessions. This concluded phase 1 of the study (namely pre-conditions). This material was then taken into the pre-implementation phase (discussed below).

## 4.5. Phase 2: Determining the Appropriateness and Acceptability of the COMPAS Training

### 4.5.1. Descriptive Characteristics of Phase 2 Participants

Two separate stakeholder groups appraised the parent training programme to determine its appropriateness and acceptability in a South African context. In order to determine appropriateness a panel of 5 subject matter experts evaluated the training programme. A second panel, consisting of a group of 25 parents who completed the COMPAS programme, rated the programme's acceptability.

The professional panel consisted of 5 professionals working in the field of autism spectrum disorders as well as the field of early childhood intervention. Their primary professional qualifications were as follows: 2 psychologists (1 clinical, 1 educational), 2 speech and language therapists and 1 occupational therapist. All had a minimum of five years' experience in their respective fields of interest. Of the 5 professionals, 3 were working in the education context (government schools for young children with special educational needs and autism) and the remaining 2 experts were employed in private practice. Twenty-five parents (who met the selection criteria specified for the main study) were recruited to the parent panel through a network of professionals working with children with ASD. The ages of the participants ranged from 27-49 with a mean age of 37 years (*SD* = 6.83). Parents had at least one child with a confirmed diagnosis of ASD and were the primary caregivers of the child. Sixty-eight percent (n=17) were female. Eighty percent (n=20) of the parents self-selected the Coloured ethnicity grouping; twelve percent (n=3) the African and eight percent (n=2) the Indian cultural group. Fifty-two percent (n=13) of the parents spoke two or more languages regularly in their home. Sixty percent of the parents (n=15) were employed full time. Twenty-four percent (n=6) of the parents had an additional child with special educational needs. The average age of the child with ASD was 5 years (*m*=5.44; *SD* =1.94).

### 4.5.2. Phase 2 Findings

#### 4.5.2.1 COMPAS Appropriateness

In order to determine the appropriateness of the initial COMPAS training programme, it was sent to a panel of subject matter experts for evaluation. During the evaluation process the panel of experts were each provided with a copy of the full COMPAS training package, this included the following materials for evaluation: PowerPoint presentation, the COMPAS training manual, and the videos of expert parents modelling the use of each communication strategy. A letter of agreement and consent was sent to each expert asking for permission to participate in the appraisal of the content relating to the parent training programme. Once the professionals had completed the feedback form, they were placed in sealed envelopes and collected by the researcher.

The professional stakeholder group (n=5) who reviewed the parent training programme in its entirety were asked to fill in a custom designed evaluation and feedback form (Professional Appropriateness Evaluation Tool) to evaluate the relevance and comprehensiveness of the content and teaching methods used in the COMPAS group parent training programme. The questionnaire made use of a 4-point Likert response format presented from 1 (*"Not relevant/comprehensive"*) to 4 (*"Very relevant/comprehensive"*). The questionnaire requested information on the following four elements; *relevance* of content, *comprehensiveness* of content, *relevance* of teaching tools and *relevance* of delivery training methods (teaching activities). Additional open-ended questions left room for the experts to comment further if they chose to. The results can be viewed in Table 2.

Table 2. *Professional stakeholder group responses to determine COMPAS appropriateness (n=5)*

| | **Frequencies of Likert scale responses** | | | |
|---|---|---|---|---|
| | **1** Not relevant/ comprehensive | **2** Needs revision | **3** Relevant/ comprehensive but needs minor changes | **4** Very relevant/ comprehensive |
| **<u>Perception about the relevance and comprehensiveness of the *goals* of the training programme:</u>** | | | | |
| **1. Relevance of content (ASD introduction and 4 communication strategies)** | 0% | 0% | 0% | 100% |

| | | | | |
|---|---|---|---|---|
| **2. Comprehensiveness of content (ASD introduction and 4 communication strategies)** | 0% | 0% | 40% | 60% |
| **3. Relevance of teaching activities (group training, small group discussions, expert parent panel discussion)** | 0% | 0% | 20% | 80% |
| **4. Relevance of teaching materials (manual, video modelling, power point presentation)** | 0% | 0% | 40% | 60% |

According to the information retrieved from the professional stakeholder group, all professionals (n=5) agreed that the content (including the four communication strategies) was very relevant for parents of children with ASD who have communication and language delay. One of the experts stated that "*Empowering parents to encourage their own child's communication and language development is vitally important, especially for those who cannot access private therapy*". Another expert commented: *"Training parents is extremely valuable, parents do not realise how valuable they are in their child's development…training in a group allows for the development of a mutually supportive environment, where parents can learn from each other, which is more powerful than learning from professionals".* Generally, the experts felt that the content was comprehensive, although some commented "*It would be clearer if you explain what to do, then showed the video examples and then do the practical session"* and *'The four communication strategies are very useful and relevant, I think that a definition of the strategy in the PowerPoint would be useful too"*. Eighty percent (n=4) of the experts agreed that the various teaching activities selected were effective, as evident in these quotes: "*Practical role-play is a very effective training method in my experience"* and "*Using the parents (in the videos) to demonstrate the use of the techniques with their children is a wonderful way to empower parents to play with their children in a therapeutic way. In this way it gives them confidence in their ability to interact with their children meaningfully. At the same time, it encourages other parents who watch the videos to want to do the same"*. In terms of teaching materials, experts agreed that the content of the manual was relevant and user-friendly. An expert from the panel remarked that *"the section in the boxed area in the manual, namely: 'To do this at home I must think about' is a nice summary of practical steps for parents to follow if they want to implement specific techniques at home".* Some of the participants provided minor improvements in the teaching activities and materials. Table 3 provides a detailed description of the key suggestions made by the professional stakeholder group.

Table 3. *Recommendations from the professional stakeholder group (n=5)*

| Aims | Results | Recommendations for change |
|---|---|---|
| **1. To ascertain the comprehensiveness (and clarity) and relevance of the content of the parent training programme** | The professionals stated that while the layout and content was informative, relevant and comprehensive they queried the clarity of the order of slides in the Power Point. | Minor adaptations were made to the sequential ordering of information in the slides. Firstly, the strategy was clearly defined to the parents, secondly information was shared on how to use the strategy at home. Thirdly, video examples were presented and finally discussion and small group role play occurred between parents and the researchers. |
| | The professionals suggested that using the same visuals in both the manual and slides would ensure consistency and conformity between key elements of the responsive interaction strategy (i.e. "wait", "look" and "copy"). | Adjustments were made to the PowerPoint slides by adding in the same visuals for 'wait, look and copy' as used in the training manual. |
| **2. To evaluate the appropriateness of the teaching activities and strategies used in the parent training programme.** | Eighty percent (n=4) of the experts agreed that the variety of teaching strategies selected were a good balance to inform participants and keep them engaged. Minor changes were suggested to improve on small group role play. One professional suggested pairing up parents so that they could practice on each other within the small group practical sessions. | As a result, parents were encouraged to take turns with their partner in the practical group sessions, so that they each received a turn to experience the different roles of 'playing' the parent and child. |

Data from the professional stakeholder group review of the training programme content and activities indicates that professionals viewed COMPAS as an appropriate PET programme in the South African context.

#### 4.5.2.2 COMPAS Acceptability

In the second part of the justification process the initial group parent training programme was presented to a group of 25 parents of children with autism spectrum disorders. They were recruited to the study through a network of professionals working with children with ASD. The purpose of this pilot was to obtain information regarding the acceptability of the content, as well as to evaluate the procedural ease with which the programme could be delivered to a group of parents in one full day (the shortest of the two training options). Prior to the commencement

of the training, parents were requested to complete a custom designed demographic questionnaire. At the conclusion of the training a custom designed questionnaire (parent acceptability evaluation tool) was completed by parents. The 18-item questionnaire consisted of 3 sections namely acceptability of the programme goals; content and procedures; and outcomes. The response format presented to the parents was a 6-point Likert scale, 6 open-ended questions were also included on the form. In total 25 parents completed the questionnaire. The results from this questionnaire can be viewed in Table 4 below.

Table 4. *Parent responses to determine COMPAS acceptability (n=25)*

| | | Frequencies of Likert scale responses | | | | | |
|---|---|---|---|---|---|---|---|
| | | 1 strongly disagree | 2 some what disagree | 3 disagree | 4 some what agree | 5 agree | 6 strongly agree |
| | **Perception about the acceptability of the *goals* of the training programme:** | | | | | | |
| **1.** | **I believe my child's communication is a high priority.** | 0% | 0% | 0% | 4% | 22% | 74% |
| **2.** | **I believe I have a role to play in teaching my child to communicate** | 0% | 0% | 0% | 7% | 11% | 81% |
| **3.** | **I want my child to be able to tell me things that interest him** | 0% | 0% | 0% | 4% | 26% | 70% |
| **4.** | **I want my child to initiate communication with me more often.** | 0% | 0% | 0% | 7% | 22% | 70% |
| | **Perception of acceptability of training programme *content* and *procedures:*** | | | | | | |
| **1.** | **I am satisfied with what was taught during the training.** | 0% | 0% | 0% | 0% | 27% | 73% |
| **2.** | **I am satisfied with the way in which the training was structured.** | 0% | 0% | 0% | 0% | 19% | 81% |
| **3.** | **I enjoyed being able to talk with other parents who have children with ASD during the training.** | 0% | 0% | 0% | 4% | 15% | 81% |
| **4.** | **I understand the strategies that were taught during the training.** | 0% | 0% | 0% | 7% | 23% | 70% |
| | **Parent perception of acceptability of *communication outcomes:*** | | | | | | |
| **1.** | **I think I will enjoy using these new strategies with my child.** | 0% | 0% | 0% | 0% | 15% | 85% |
| **2.** | **These new strategies will improve the way my child and I communicate with each other.** | 0% | 0% | 0% | 8% | 19% | 73% |
| **3.** | **I believe this training will help me to understand my child better.** | 0% | 0% | 0% | 4% | 22% | 74% |
| **4.** | **I would recommend this training to a friend who was concerned about his/her child's communication skills.** | 0% | 0% | 0% | 0% | 11% | 89% |
| | **Parent perception of competence *outcomes*:** | | | | | | |
| **1.** | **I can teach language to my child while we play.** | 0% | 0% | 0% | 4% | 22% | 74% |
| **2.** | **I can teach language to my child during everyday routines.** | 0% | 0% | 0% | 4% | 22% | 74% |
| **3.** | **I am confident that I can use these strategies with my child.** | 0% | 0% | 0% | 8% | 17% | 75% |
| **4.** | **I think I can teach other family members what I learnt at the training.** | 0% | 0% | 0% | 15% | 27% | 58% |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| **5.** | **I am confident that I can use at least 1 of the new strategies at home with my child.** | 0% | 0% | 0% | 0% | 15% | 85% |
| **6.** | **I am confident that I can now support my child so he can learn new words and phrases.** | 0% | 0% | 0% | 4% | 15% | 81% |

Seventy-five percent of parents (n=19) agreed that they could teach language to their child while they played. Additionally, 19 parents (75%) felt competent that they could teach their child language during everyday routines. Seventy-five percent of parents (n=18) indicated that the training helped them to better understand their child's current level of communication and that it strengthened their belief in playing a pivotal role to teach their child how to communicate. Most parents (n=18) also indicated a deep desire for their children to initiate communication with them, after the training a participant from the group commented: *"I (have) already started trying some methods. I let him lead and so we learn together"*. Encouragingly, the vast majority, 84% of parents (n=21) reported that they were confident that they could use at least one of the new strategies with their child at home. One parent stated *"…we are practising what we learnt, and it makes a great difference for my son"*.

In addition to completing the questionnaires, parents were asked for their recommendations or areas for improvement to the COMPAS programme. They were requested to identify any aspects relating to parenting competence which were not included in the training, but that which they thought should be. Lastly, parents were required to list any challenges that would prevent them from trying the strategies at home with their child. Recommendations for improvements from the parent panel can be viewed in the Table 5 below.

Table 5. *Recommendations from the parent panel (n=25)*

| Aims | Results | Recommendations for change |
|---|---|---|
| **1. To determine the acceptability of the COMPAS content and training procedures** | Parents noted that the video modelling content could include more examples of verbal children using phrase speech (consisting specifically of two to three-word phrases). The parents of children who were more verbal said that they found it more difficult to relate to video examples of techniques being used with children who were minimally verbal (single words) to non-verbal. | Five additional videos of a verbal child using phrase speech with his mother during the modelling of various techniques was then included in the video content of the programme to provide more diversity in the communication abilities we demonstrated. |
| | Some of the parents suggested having a live demonstration where parents | The suggestion of having presenters work on an individual basis with the |

| | | |
|---|---|---|
| | brought their child with ASD to the training venue and the presenters could work with that child, demonstrating the implementation of the communication strategies. | parent and their child would have changed the focus of the PET programme to a coaching session instead. Coaching requires greater time and use of resources.<br>Additionally, children with autism do not manage change in their routine well and are often anxious. Having a child brought into the training environment unexpectedly while expecting them to perform on demand with a large group of unfamiliar adults observing them would have likely had a contradictory effect on parent training. Therefore, the suggested changes by parents were not incorporated. |
| | The parents suggested having a hard copy of the notes related to the slides and information to take home to help them implement what they had learnt during the training. They noted that having written material related to the content would assist them greatly as a reference to what they learnt and save time from having to write down information from the PowerPoint slides. | As a result of the parents' suggestions a printed training manual was conceptualised and developed to accompany the parent training programme. The 25-page manual consisted of an introduction to ASD and its related communication disorders. Each of the four communication strategies were clearly defined in the manual along with photographs representing the videos and toys shown during the training. |
| | The parents suggested that the manual included a short summary of the technique for when parents needed to implement the new techniques at home. | This was addressed in two sections in the manual; '*steps to consider before using this strategy successfully*' and '*to do this at home I must think about*'. Additionally, a section was included for parents to reflect on their successes and challenges which they could write down in the manual. |
| | The parents indicated that they were unsure of where to buy developmentally appropriate toys for their children and requested a list of suggestions on where to buy toys similar to those used during the training sessions. | A section was added to the end of the manual listing local toy stores and online sites selling toys for purchase similar to those used in the training programme. |
| | The parents felt that a lack of available social support, related to their child's diagnosis contributed towards further social isolation. | The researchers responded to the parent's feedback and began an interactive Facebook page accessible for all parents who completed the training to regularly post updates and keep in contact.<br>(Parents also initiated a social WhatsApp chat group to keep in regular contact with each other.) |

| | | |
|---|---|---|
| | The parents stated that the programme was lacking certain aspects beyond language that would have increased the success of the programme in their opinions; for example, the parents noted that they would have liked further instructions about how to manage behaviour and tantrums | The primary focus of the PET programme was to teach communication strategies and not behaviour management. Therefore, the suggested changes by the parents were not incorporated. |

Data from the parent panels' review of the training programme content and activities indicates that parents viewed COMPAS as an acceptable intervention which was valuable in helping them to communicate more effectively with their children.

### 4.6. Summary

This chapter outlined the rationale for the inclusion of the 4 communication strategies, as well as the teaching activities incorporated into the COMPAS training programme. The phase 2 participants were described. The two groups of stakeholders deemed COMPAS to be an appropriate and acceptable PET programme. All professionals indicated that the content was comprehensive and relevant, and that the training manual was user friendly. Most of the parents felt confident they could teach their child new language during play and routines after completing the training, and indicated that they felt confident in using at least one communication strategy at home with their child.

# Chapter 5:

# Implementation of the COMPAS Programme

## 5.1. Introduction

In this phase of the research study, the group-based parent training programme was administered to two groups of parents who met the selection criteria stipulated in 5.2 below. Parents were allocated to one of two groups depending on parent availability and work commitments. Parents self-selected to attend a morning only group (which ran over three Saturday mornings) or a full day training (which was administered over one full day on a Saturday). This chapter outlines the design and sampling procedures used in phase 3 and presents an analysis of the results of the study. The internal consistency of the measures is calculated as well as the changes in outcome measure scores after intervention. The percentage of parents who showed reliable improvement across parenting interactions and self-efficacy is determined. We investigate key demographic and baseline characteristics which predict the outcome measure scores using linear regression.

## 5.2. Descriptive Characteristics of Phase 3 Participants

A total of 45 parents were contacted via the Western Cape Education Department's centralised waiting list. All parents who were contacted telephonically or via email had a child diagnosed with autism spectrum disorder. These children were referred to the government waiting list by private and state practitioners who diagnosed them. Children referred to the government waiting list were awaiting educational services and school placement. Of the 45 parents contacted, 35 parents expressed interest and agreed to participate in the COMPAS training programme. A total of 31 parents started and completed the group training programme, 21 parents participated in the COMPAS programme which ran over three Saturday mornings, and 10 parents participated in the COMPAS program which ran over one full Saturday. Four parents (2 in each of the groups) agreed to attend the training then did not participate on the day, the primary reasons for non-attendance were due to parent illness or injury and unforeseeable cancellation of babysitters. Two parents who agreed to participate in the

COMPAS delivery which ran across three Saturday mornings, did not attend the second session. However, all parents attended the first and last sessions.

The parents had a mean age of 33.8 years (*SD* = 5.5). The majority (n=28) were female. Seventy one percent (n=22) of the parents self-selected the Coloured ethnicity grouping; 16 percent (n=5) selected the Black African grouping, 6 percent (n=2) the White ethnic group, and 3 percent (n=1) the Indian ethnic group. Fifty-eight percent (n=18) indicated they primarily spoke English in their home, while ten percent (n=3) indicated that they spoke isiXhosa and English and about twenty-two percent (n=7) of parents indicated they speak English and Afrikaans. Ninety-two percent of the parents indicated that they were employed full time (n=23). Therefore, the majority of parents who attended the training were females of the Coloured ethnic group, who were employed and spoke English to their children at home (see Table 6).

Table 6. *Demographic Characteristics of Parents*

| | *n* | % |
|---|---|---|
| **Gender (female)** | 28 | 90 |
| **Gender (male)** | 3 | 10 |
| | | |
| **Culture/Ethnicity** | | |
| Coloured | 22 | 71 |
| Black | 5 | 16 |
| White | 2 | 7 |
| Indian | 1 | 3 |
| Other | 1 | 3 |
| **Language** | | |
| English | 18 | 58 |
| isiXhosa + English | 3 | 10 |
| Afrikaans + English | 7 | 22 |
| Other (French/Shona + English) | 3 | 10 |
| **Employed (yes)** | 25 | 81 |
| Full-time | 23 | 92 |
| Part-time | 2 | 8 |
| **Education** | | |
| Grade 1-9 | 2 | 7 |
| Grade 10-12 | 13 | 42 |
| Diploma/certificate | 5 | 16 |
| Degree | 11 | 35 |

Key family characteristics can be viewed in Table 7. The number of children parents had ranged from 1-4, with a mean of 1.9 (*SD*=0.8). Only 2 parents (6%) had other children with special educational needs (both were diagnosed with ASD). The number of adults in the home ranged from 1-5, with a mean of 2.5 (*SD*=1.0). The ages of the child with ASD ranged from 2.3-7.11 years (27-95 months) (*m*=56.2; *SD* =17.4). The age at which this group of children were diagnosed with ASD ranged from 23-65 months (M 35.5; *SD* 10.1).

Table 7. *Key Family Characteristics*

| | Mean (SD) | Range |
|---|---|---|
| **Demographics** | | |
| Age of parent | 33.8 (5.5) | 20-48 |
| Adults in home | 2.5 (1.0) | 1-5 |
| Number children | 1.9 (0.8) | 1-4 |
| Age of child (months) | 56.2 (17.4) | 27-95 |
| Age child diagnosed (months) | 35.5 (10.1) | 23-65 |

### 5.3. Phase 3 Findings

The training was administered in two formats: namely over three Saturday mornings (n=21) or over one full Saturday (n=10). However, due to small numbers in group 2 we compared the two groups of participants on key demographic variables to determine functional equivalence of the groups. There were no between-group differences for any demographic variables (all *p*s > .081) which indicated equivalence. Therefore, all statistical analyses are run with the two groups combined (n=31). All data are normally distributed and therefore parametric statistics are used for all statistical analyses.

#### 5.3.1. Treatment Session Integrity

The integrity checklist was completed at each session by one of the facilitators to ensure that important aspects of the training were included and not overlooked. The checklist consisted of 8 procedural aspects, the total score range across all sessions was 100%, detailed description of the checklist can be viewed in appendix 10. This indicates that the sessions were followed the same format as agreed upon during the development of the programme.

### 5.3.2. Reliability and Internal Consistency of the Outcome Measures

The PSOC had a Cronbach's Alpha of .78, the PSEMI an alpha of .95, and the PICCOLO an alpha of .75 indicating all measures showed good internal consistency and could be reliably used in this context (see Table 8).

Subscales on the PSEMI and PSOC indicated fair to good internal consistency (all Cronbach's Alpha's > .65). However, most subscales on the PICCOLO had poor reliability, especially the Encouragement subscale (Cronbach's Alpha = .06). Removing item 5 from the scale would have improved the internal consistency of the affection (.50), responsiveness (.69), and encouragement scales (.23), however, because the overall measure's internal consistency was acceptable (.75) with item 5 included, the complete scale as recommended by the developers was retained in all subsequent analyses.

Table 8. *Cronbach's Alpha for each Measures Subscales and Total Score*

| | Number of items | Cronbach's Alpha |
|---|---|---|
| PICCOLO-Affection | 7 | .48 |
| PICCOLO-Responsiveness | 7 | .63 |
| PICCOLO-Encouragement | 7 | .06 |
| PICCOLO-Teaching | 8 | .53 |
| *PICCOLO- Total* | *29* | *.75* |
| PSEMI-Affection | 7 | .69 |
| PSEMI-Communication | 7 | .86 |
| PSEMI-Discipline | 8 | .85 |
| PSEMI-Learning | 7 | .85 |
| PSEMI-Play | 7 | .81 |
| PSEMI-Routines | 7 | .80 |
| *PSEMI- Total* | *43* | *.95* |
| PSOC-Efficacy | 8 | .66 |
| PSOC-Satisfaction | 9 | .71 |
| *PSOC-total* | *17* | *.78* |

### 5.3.3. Baseline Measures of Child Functioning

Of the 34 children with ASD, 33 were assessed formally using the Preschool Language Scale 5$^{th}$ edition (PLS5) which is a standardized language assessment tool. PLS testing was abandoned with one child who presented with high levels of anxiety and extremely challenging behaviour. A parent questionnaire regarding language ability was completed with his mother

to determine language comprehension and expressive skills. Any standard score below 60 is 2 standard deviations below the average for the test and indicates a significant language delay. Children presenting with language abilities in this range have a significant language impairment would be eligible for language intervention. The range of standard scores for the receptive language scale was 50-82 (M 54.2; *SD* 8.4). The range of standard scores for the expressive language component was 50-94 (*M* 57.3; *SD* 12.7). Lastly, PLS total language age equivalents ranged from 6-60 months (*M* 22.8; *SD* 12.9).

Parents completed ECBI questionnaires for all 34 children. The ECBI allows parents to identify problem behaviours their child engages in, and requests parents to rate the intensity of their child's problem behaviours. Standard scores for problem behaviour on the ECBI indicated a mean score of 60.8 (*SD*= 10.4) with range 41-88. For the intensity subscale a mean score of 63.3 (*SD*=22) with range (40-171) was noted. Eighteen of the 31 children (58.1%) met the intensity and problem cut off criteria on the ECBI.

### 5.3.4. Changes in Outcome Measures from Baseline to Post-Intervention

Parents showed improvement in parent child interaction after the training (49.2 ± 6.2) compared to baseline scores (40.1 ± 7.2), a statistically significant change of 9.1, $t(30) = -3.19$, $p < .05$, $d = 1.26$ (see Table 4 and Figure 1). Parents showed an increase in parenting self-efficacy on the P-SEMI after the training (99.5 ± 25.7) compared to baseline scores (110.7 ± 32.4), a statistically significant change of (11.2), $t(30) = 3.01$, $p < .05$, $d = 0.35$. However, there was no significant change in efficacy as measured by the PSOC change score (3.4), $t(30) = -2.04$, $p = .05$, $d = 0.30$ (see Table 4 and Figure 1), the *p*-value approached significance and the a moderate effect size was reported.

Table 9. *Baseline and post intervention scores for all outcome measures*

| | Baseline | Post-intervention | Change score | 95% CI | *t* | *p* | *d* |
|---|---|---|---|---|---|---|---|
| PICCOLO-Affection | 11.8 (2.0) | 12.7 (1.6) | 0.9 (1.6) | 0.3 – 1.48 | -3.19 | .003* | 0.45 |
| PICCOLO-Responsiveness | 10.5 (2.6) | 12.1 (2.2) | 1.6 (2.0) | 0.9 – 2.3 | -4.48 | <.001** | 0.62 |
| PICCOLO-Encouragement | 9.8 (1.9) | 12.3 (1.8) | 2.5 (1.7) | 1.9 – 3.1 | -8.29 | <.001** | 1.32 |
| PICCOLO-Teaching | 7.9 (3.1) | 12.1 (2.8) | 4.1 (3.8) | 2.7 – 5.5 | -5.98 | <.001** | 1.32 |
| PICCOLO-Total | 40.1 (7.2) | 49.2 (6.2) | 9.1 (6.5) | 6.7 – 11.5 | -7.78 | <.001** | 1.26 |
| | | | | | | | |
| PSEMI-Affection | 11.8 (4.2) | 10.5 (2.9) | -1.3 (2.9) | -0.2 – (-2.4) | 2.46 | .020* | 0.31 |
| PSEMI-Communication | 18.9 (7.3) | 16.7 (5.6) | -2.1 (5.1) | -0.3 – (-4.0) | 2.31 | .028* | 0.29 |
| PSEMI-Discipline | 23.3 (7.3) | 21.5 (7.2) | -1.8 (4.2) | -0.3 – (-3.4) | 2.37 | .024* | 0.25 |
| PSEMI-Learning | 19.3 (6.4) | 16.9 (5.1) | -2.4 (5.3) | -0.4 – (-4.3) | 2.46 | .020* | 0.38 |
| PSEMI-Play | 17.9 (6.1) | 16.4 (4.6) | -1.6 (4.3) | -0.01 – (-3.2) | 2.08 | .046* | 0.26 |
| PSEMI-Routines | 19.5 (6.5) | 17.4 (4.8) | -2.0 (4.5) | -0.4 – (-3.7) | 2.53 | .017* | 0.31 |
| PSEMI-Total | 110.7 (32.4) | 99.5 (25.7) | -11.2 (20.8) | -3.6 – (-18.8) | 3.01 | .005* | 0.35 |
| | | | | | | | |
| PSOC-Efficacy | 33.8 (5.7) | 35.4 (5.2) | 1.5 (5.0) | -0.32 – 3.4 | -1.69 | .102 | 0.26 |
| PSOC-Satisfaction | 32.7 (7.1) | 34.6 (6.1) | 1.8 (6.7) | -0.61 – 4.29 | -1.53 | .136 | 0.25 |
| PSOC-Total | 66.6 (11.2) | 69.9 (8.9) | 3.4 (9.2) | -0.01 – 6.7 | -2.04 | .050 | 0.30 |

*Note*. For the PSEMI measure, a lower score is better. For the PICCOLO and PSOC, a higher score is better.
*d* = Cohen's *d*, calculated as: (baseline mean – post-intervention mean) / SD at baseline.
*$p < .05$. **$p < .003$ (Bonferroni corrected for performing 15 statistical tests)

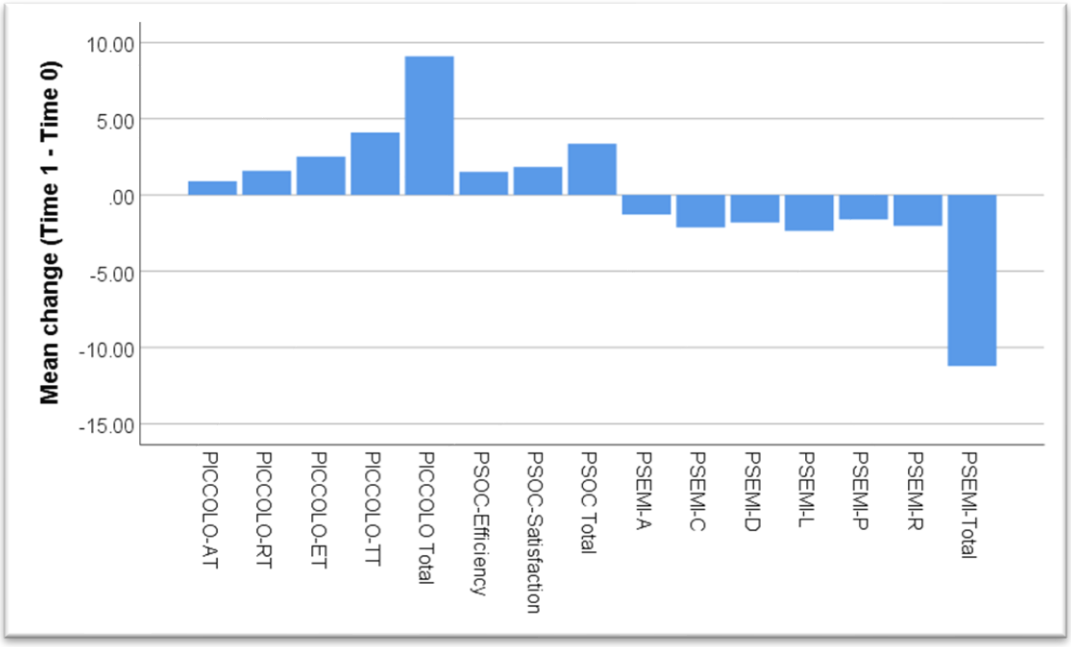


*Figure 3.* Average change in PICCOLO, PSOC and PSEMI measures

Therefore, for parenting child interactions we can accept the hypothesis that COMPAS improves parent-child interaction. Therefore, P-SEMI data supports the hypothesis that COMPAS improves parental self-efficacy.

### 5.3.5. Documenting Reliable Change

The reliable change index has been used in numerous caregiver coaching and education and training programmes for parents of children with disabilities to indicate whether change is reliable and clinically significant. Published data typically indicate reliable and significant change for 30%-50% of parents enrolled in parent coaching and education and training studies (Ginn, Clionsky, Eyberg, Warner-Metzger, & Abner, 2017; Kristelle et al., 2018; Leung, Pang, & Taylor, 2013; Sofronoff, Dark, & Stone, 2011). Results from the COMPAS training can be viewed in Table 10.

Table 10. *Percentages of Parents Showing Reliable Change*

| | Reliable improvement | Some improvement | No improvement |
|---|---|---|---|
| PICCOLO | 14 (45%) | 16 (52%) | 1 (3%) |
| PSEMI | 10 (32%) | 12 (39%) | 9 (29%) |
| PSOC | 5 (16%) | 16 (52%) | 10 (32%) |

Analysis of reliable change using RCI criteria indicated that 14 (45%) of parents had a reliable increase (> 9.98) on the PICCOLO, 5 (16%) had a reliable increase (> 14.59) on the PSOC, and 10 (32%) had a reliable decrease (> 19.88) on the PSEMI (see Table 10). These percentages are comparable to percentages reported in published literature.

### 5.3.6. Baseline Predictors of Post Intervention Self-Efficacy Scores

Three separate backwards linear regressions were conducted to determine whether pre-intervention variables (PLS Total Language Age-Equivalent Score, ECBI Behaviour Score, Maternal Age and Maternal Education) predicted improvement in competence (change scores on the PICCOLO, PSEMI and PSOC) post-intervention. None of the data violated assumptions of normality or independence (see Table 11). VIF figures were close to 1, providing evidence to suggest no problems with multicollinearity. All variables were coded as continuous, except maternal education. This variable was dummy coded with 2 levels: < matric education and > matric education, such that < matric education was the reference group.

Table 11. *Correlations between Outcome and Predictor Variables*

| | Change PICCOLO | Change PSEMI | Change PSOC | PLS | ECBI | Maternal Age | Maternal Education |
|---|---|---|---|---|---|---|---|
| Change PICCOLO | 1.00 | | | -.194 | -.162 | .103 | -.128 |
| Change PSEMI | | 1.00 | | -.398* | -.089 | .002 | .085 |
| Change PSOC | | | 1.00 | -.365* | -.027 | -.257 | .105 |
| PLS | | | | 1.00 | -.100 | -.156 | -.200 |
| ECBI | | | | | 1.00 | -.141 | -.132 |
| Maternal Age | | | | | | 1.00 | .228 |
| Maternal Education | | | | | | | 1.00 |

*Note.* Pearson's *r* correlation coefficients are presented. *$p < .05$.

Table 12. *Final Regression Models Summary Table*

| Model | R | R Square | Adjusted R Square | Std. Error of Estimate | R Square Change | F | F Change | Sig. of F change | Durbin-Watson | p-value |
|---|---|---|---|---|---|---|---|---|---|---|
| 1.PSEMI | .398 | .159 | .128 | 19.01 | -.028 | 5.27 | .936 | .342 | 1.61 | .029* |
| 2.PSOC | .484 | .234 | .178 | 8.45 | -.014 | 4.14 | .467 | .500 | 2.04 | .022* |

1. Predictors: Pre-intervention PLS Score. *$p < .05$
2. Predictors: Pre-intervention PLS Score. *$p < .05$

All variables were entered into one block in the regression analysis. This was exploratory to see which significantly correlated predictor variables would be significant predictors of improved competency. Results of the regressions indicated that only the PLS Score predicted change in PSEMI and PSOC. The final PSEMI regression model explains 13% of the variance in participants' self-efficacy improvement ($R = .398$, $R^2 = .128$, $F$ [1,29] = 5.27, $p = .029$; (see Table 12). The final PSOC regression model explains 18% of the variance in participants' self-efficacy improvement ($R = .484$, $R^2 = .178$, $F$ [2,29] = 4.14, $p = .022$; see Table 12). The regression coefficients suggest that lower PLS Scores predicted improved self-efficacy post-intervention (see Table 13).

Table 13. *Coefficients for Predictors in Final Regression Models*

| Variables | *b* | Std. Error | Beta | *t* | *p* | 95% CI |
|---|---|---|---|---|---|---|
| **PSEMI** | | | | | | |
| Constant | -24.59 | 7.15 | - | -3.44 | .002* | -39.23 – (-9.94) |
| PLS Score | 0.63 | 0.27 | 0.40 | 2.30 | .029* | 0.07 – 1.19 |
| **PSOC** | | | | | | |
| Constant | 28.76 | 10.73 | - | 2.68 | .012* | 6.74 – 50.78 |
| Maternal Age | -0.55 | 0.12 | 0.42 | -2.44 | .070 | -0.55 – (-0.05) |
| PLS Score | -0.30 | 0.29 | 0.32 | -1.89 | .022* | -1.14 – 0.05 |

Thus, none of the variables investigated (PLS Total Language Age-Equivalent Score, ECBI Behaviour Score, Maternal Age and Maternal Education) predicted improvement in parent child interaction, however the baseline PLS score predicted self-efficacy improvement post intervention.

### 5.4. Summary

This chapter presented the design and sampling procedures used in the study. A description of participants was provided. Characteristics of the parents and baseline measures of child characteristics were described. The internal consistency of the tools was explored and change in outcome measures following the training were reported. Data indicates that the COMPAS training resulted in significant improvements in both parent child interactions as well as parenting self-efficacy, with moderate to large effect sizes. The reliable change index indicates that 97% of parents showed some improvement in parent child interaction and approximately

60% showed some improvement in parenting self-efficacy. Finally, linear regression indicates that child language level at baseline (as measured by the PLS) predicted self-efficacy improvements post-intervention.

# Chapter 6

# Discussion and Conclusion

## 6.1. Introduction

The aim of this research study was to develop and implement a group-based parent education and training programme to improve parents' abilities to facilitate communication interaction in their young children and measure the effect on parental self-efficacy of parents with children with ASD. The communication parenting strategies (COMPAS) programme was developed and refined based on the available literature from naturalistic developmental behavioural interventions, existing PET programmes for parents of children with ASD and parenting self-efficacy domains.

The two main hypotheses of the study were first, that there would be an increase in parent-child interaction and parent self-efficacy would be enhanced by increasing parent knowledge and skills. Third, that a brief (10-12 hour) group parent education and training programme (COMPAS) is a feasible and appropriate early intervention for parents of young children with autism in a LMIC context.

## 6.2. Main Findings

### 6.2.1. COMPAS Increases Positive Parent Child Interaction in a LMIC Context

In the present study the primary outcome was improving positive parent-child interaction. Changes in the quality of parenting interactions was measured using the Parenting Interactions with Children: Checklist of Observations Linked to Outcomes (PICCOLO). This standardised, validated tool provides a useful framework for interventionists to examine the interactions between parents and their young children. It informs the interventionist about parental capacities and strengths, making it easier for the therapist to keep the parent-child dyad in mind (Anderson et al., 2013; Roggman et al., 2013; Wheeler et al., 2013). This perspective stems from a strengths-based approach, which assumes that every parent has unique strengths and capacities that can be accessed to address challenges and concerns (Roggman et al., 2013).

The current study reported significant improvement in positive parent child interaction after receiving training. Improvement was recorded for 97% of participants and forty five percent (n=14) of participants demonstrated reliable improvement in parenting interactions on the

PICCOLO tool. These results are comparable to a parent-mediated social-communication intervention for young children with ASD that was developed in a community setting to improve child spontaneous language (Ingersoll & Wainer, 2013). These findings demonstrate that parents' interactional style with their children can be enhanced through parent education and training interventions.

Parenting interactions are important because they are linked to positive child outcomes related to cognitive, social and language development (Wheeler et.al., 2013). Furthermore, positive parent interactions can lead to developing behaviours that optimise the relationship between parent and child in support of continuing positive interactions and facilitating communication development (Ingersoll & Wainer, 2013). Early childhood literature exploring parental responsiveness suggests that parental responsivity is dynamic and continues to change over time as children's initiations change with development. Therefore, for parents to be considered highly responsive, they must provide developmentally appropriate and timely responses to the child's subtle and overt communicative bids. Shire and colleagues (2017) suggest that responsive behaviour should be appropriately combined with additional teaching strategies in order to properly support children's development. Parental verbal responsivity has been associated with increases in social responsivity in children with ASD and can lead to gains in prompted and spontaneous use of language (Landa, 2018; Stone & Yoder, 2001). Furthermore, parental responsiveness has been linked to the amount of time children spend engaging in shared attention (*joint attention*) during an activity with their parents. In children with ASD, social communication (verbal and non-verbal communication used for the purposes of sharing interest with others) and language are developmentally intertwined, as social communication predicts current and later language development in young children with ASD (Schreibman et al., 2015).

During the COMPAS programme, parents received 10-12 hours of intervention focusing on four social-communication strategies, all of which were used to increase parent responsiveness as a means to improve parent-child interaction. The COMPAS intervention focuses on how to: structure the environment for teaching and learning language through play (environmental arrangement), engage the child in verbal and non-verbal interactions (contingent responding), use daily routines and developmentally appropriate play routines to create opportunities for prompting production of new vocabulary and language (creating opportunities to talk) and model and expand children's language. Parents are taught the developmentally appropriate sequence of these target communication and play skills. They are also taught within the group

to use the four main strategies to target developmentally appropriate skills within the context of playing with toys and interacting with familiar people. Current PICCOLO data suggests that parents made significant improvement on the teaching subscale, which documents parents' ability to provide contingent responses to children's attempts to communicate.

Parent responsiveness hinges on the ability of the parent to clearly and quickly detect their child's clear intent to communicate. For children who present with delays in their social communication skills, as is common in children with autism, the clarity of their intentional communicative behaviour may be less clear and therefore more difficult for the parent to notice. These subtleties in communicative attempts, include eye-gaze, facial expression, gestures and physical positioning of the child. Thus, using education and training to support parents' ability to notice and contingently respond to emerging social communication attempts can provide multiple learning opportunities for the child as the parent scaffolds their behaviours (Hancock & Kaiser, 2006). Existing literature on responsive parenting styles also include limited redirection of the child's attention to the adult's interests and fewer adult commands, as these are associated with a more directive interactional style (Schreibman et al., 2015). Prata and colleagues (2018) advocated the advantageous effects of group parent training programmes on the interactions of parents and their young children. Their review demonstrated that parents who received intervention were less directive and more positive during their interactions with their children compared to the untreated control group.

The children in this study demonstrated baseline PLS language scores which indicated significant language delays. Thus, these results may be especially important for the population of minimally verbal children with ASD who demonstrate significant difficulties with social-communication skills. These promising findings indicate that parent-child interaction improved after participation in the COMPAS parent-training programme, despite the children in the study having significant language delays. Findings in autism research and treatment encourage a focus on enhancing immediate and contingent responding by parents to children's signals as an important strategy to support social interactions between caregivers and their children with autism (Hampton & Kaiser, 2016; Hancock & Kaiser, 2006; Schreibman et al., 2015). A responsive parenting interaction style is when parents notice and then contingently act on their children's interests, speech, body language and related non-verbal communication (Hampton, Harty, Fuller, & Kaiser, 2019; Hancock & Kaiser, 2013). Strategies related to adult's contingently responding to children's behaviour appears to be well established in parenting coaching programmes (Franz & Dawson, 2019; Hampton & Kaiser, 2016; Hancock & Kaiser,

2006; Ingersoll, Straiton, Casagrande, & Pickard, 2018; Schreibman et al., 2015). However, COMPAS is one of the few group-based interventions which teach this strategy. Therefore, intervention approaches that support parents to develop strategies for successful social interaction should be a clear route to choose for early intervention in children with ASD and significant language delays. (Oono et al., 2013; Wainer & Ingersoll, 2015).

The results of the study suggest that parents' responsiveness towards their child and their ability to create teaching opportunities during interactions could be increased by attending a 10-hour group training programme. In light of these factors, group parent training has demonstrated to be a cost-effective way of providing early intervention in a resourced constrained setting, while additionally providing unique gains in influencing the interaction style of the parent-child dyad (Dawson-Squibb, Davids, Harrison-Johnson, et al., 2019). Yet, overall there is a paucity of literature focusing on group-based training to increase parent-child interactions in the social-communication domain. These findings should encourage future research to focus on embedding important strategies into PET programmes to enhance and support social-communication interactions between parents and their young child with autism.

### 6.2.2. COMPAS Increases Parenting Self-Efficacy in a LMIC Context

Self-efficacy is founded on Bandura's social cognitive theory and is the belief that one can execute the necessary steps needed to achieve a goal (Bandura, 1971; Kardong-Edgren, 2013). In short, a high level of parental self-efficacy will lead to parents thinking and acting in ways that will optimise their child's development. The data from this study support the study's hypothesis and indicate that the COMPAS parent education and training programme improved parents' self-efficacy. These findings were statistically significant and therefore we can conclude that COMPAS is a brief PET programme that is effective in changing parental self-efficacy levels.

Research shows that the effectiveness of parent training programmes in increasing PSE is not only reliant on the characteristics of the programme content taught or teaching activities employed, but more importantly on the types of activities that are integrated into the programme (Hohlfeld et al., 2018; Wyatt Kaminski et al., 2008). According to Wyatt Kaminski et al. (2008), programmes associated with greater effect sizes for PSE incorporated the following delivery techniques used to engage parents and teach pertinent content, these include:

group discussions, small group role play and homework exercises that involved practising newly acquired skills with their children.

From a theoretical perspective Bandura (1969) states that there are four primary methods in which the development of personal self-efficacy can be modified, namely, vicarious experience (watching challenging activities being carried out and achieved by competent models), direct experience or enactive mastery (personal experiences of managing efforts towards accomplishments), verbal persuasion from others; and emotional arousal experienced in a situation, such as stress or anxiety and/or fear. According to Bandura (1986) self-efficacy beliefs grounded on direct experience is the most influential source of efficacy information and is less susceptible to change brought about by the other three factors. As such, mastery experiences are crucial for the maintenance or improvement of self-efficacy beliefs, as they form the basis against which performances are judged, in short successes build a robust sense of efficacy. Vicarious learning (or watching others attain success) have also been successfully used to enhance self-efficacy beliefs across a range of behaviours (Bandura, 1986). It is therefore possible to use these primary methods to actively facilitate learning a new skill, as well as influence perceived self-efficacy levels within a specific task, such as parent-child interaction.

Since the literature suggests that parental self-efficacy can be improved after participation in PET programmes and the results from the current study corroborate these findings, the teaching activities employed in the COMPAS programme used to modify perceived levels of PSE are now reviewed. The first and most important contributor to perceived parenting efficacy is personal experience (enactive mastery), this results from prior accomplishments in certain activities. Therefore, by allowing parents to role play the communication strategies in small groups with other parents they experienced success in a situation previously perceived as challenging. In addition, providing guided steps and an opportunity to implement the strategy at home with their child would also have bolstered a sense of personal mastery.

A second likely method that enhanced PSE in this study is by using vicarious experiences. Five expert parents; regular mothers and fathers of autistic children were incorporated into the training as video models who competently carried out routine and play activities with their own child while implementing specific communication teaching strategies. This allowed parent participants who observed the competence modelled by the expert parents in the videos the opportunity to re-evaluate their own mastery abilities in relation to similar challenges they may

experience. It is important to note that one of the reasons for incorporating the expert parents into the study was that they were relatable to the parents attending the training. Both the expert parents and the parent participants are involved in raising their young child with autism. According to Bandura (1986) vicarious learning is especially beneficial when individuals see themselves as being similar to the observed model. Therefore, having the expert parents provide the video modelling of the strategies (instead of professionals) may have also contributed towards PSE improvement.

A third mechanism included in the training programme used to potentially increase parents' feelings of competence and their belief in their own abilities to enhance communication with their child is through the use of verbal and social persuasion, wherein the expert parents and speech therapists acted as facilitators providing positive and constructive verbal feedback to parents in terms of their capabilities related to the task during small group role play and larger group discussions. Evidence indicates that encouragement and support from others is beneficial in improving self-efficacy and belief in ability, however discouragement is believed to have the opposite effect (Coleman & Karraker, 1998; O'Donovan et al., 2019; Wittkowski et al., 2016).

Lastly, a fourth way parents' self-efficacy was intended to be modified is through emotional and physiological arousal. Parents of children with developmental disabilities, such as autism, may experience increased psychological stressors such as fear, anxiety and fatigue which may make it harder for them to experience successfulness (Coleman & Karraker, 1998; Smetana, 1995). Therefore, by increasing parent's knowledge and skills during the PET group training, as well as providing informal support which is present in the group-based format, is known to reduce negative emotional arousal responses and enhance performance. The subsequent result is that parents' perceived sense of self-efficacy is increased (Bandura, 1969). The emotional support parents derived from the group parent training was possibly as a result of the cumulative benefits of teaching activities presented in group format, rather than the inclusion of one specific standalone teaching activity, although participants did comment on the value of the expert parent panel presentation. Parents also initiated their own social WhatsApp chat group to remain in contact and to initiate future social group activities.

Despite the reported difficulties in early detection of autism, the mean age of the children in this study was 56 months. Hohlfeld et al. (2018) reported parent training programmes targeting parents of younger children is more beneficial in increasing PSE outcomes than training

initiated after the child is 5 years of age. The current study's findings corroborate this review and in so doing highlight the value of early intervention. The authors of the systematic review postulate that the reason for greater improvements in PSE in the parents of younger children could be because it is easier to identify developmentally appropriate activities and skills and provide opportunities to increase feeling of competence within developmental domains, than it is to identify skills to teach parents of older children (Hohlfeld et al., 2018). Therefore, clinicians need to consistently identify ways of providing early detection and diagnosis for children with autism and directing families of newly diagnosed children toward evidence-informed PET programmes.

As a consequence of incorporating evidence-informed teaching activities into the COMPAS programme; namely small group role play, video modelling, group discussions, an expert panel discussion and a specifically developed manual incorporating homework exercises, and targeting parents of children under the age of 5, these techniques had a positive impact on enhancing parental self-efficacy. Thus, the design of future PET programmes should consider not only the content of the programme, but also the type of activities integrated in the delivery methods, as these will most likely affect the potential of the programme to enhance PSE.

### 6.2.3. COMPAS is Acceptable and Appropriate to Stakeholders in a LMIC Context

The content and delivery of the COMPAS group programme was evaluated by stakeholders consisting of subject matter experts (experienced professional clinicians) working within the field of autism as well as parents of young children with autism. Both panels appraised the programme separately. The COMPAS programme was rated as both acceptable and appropriate to parents and professionals. Professionals agreed that the content was relevant, as well as sufficiently comprehensive for the target audience and time allocated. They also agreed that the custom designed training manual was user-friendly and that the training activities were effective. Findings from the parent group indicated that the training helped them to better understand their child's current level of communication. Parents felt confident that they could implement the strategies at home, and they felt competent that they could teach language to their child during everyday routines, and play.

With regard to stakeholder involvement, professionals should be encouraged to consider 'local community' parents as facilitators in PET programmes. Two challenges with existing PET programmes is that firstly, most professionals are not parents of children with disabilities and

so there is a mismatch when using professionals as role models for demonstrating skills, such as during role play activities. Secondly, some PET programmes make videos available where parents demonstrate the use of skills, but many of these parents do not live in the same country as the participants and therefore it may be hard for parent participants to identify with (Dawson-Squibb & de Vries, 2019). To address these barriers, facilitators in the COMPAS group intervention programme, were a mix of professionals and local community parents. Additionally, footage of local community parents was used during video modelling sessions to create the right kind of 'profile' to make mastery of the communication skills seemed more attainable to the parent participants. Lastly, the use of parent facilitators likely bolstered PSE as parent facilitators have been where the current participants are and could provide a unique kind of empathy that professionals can seldom match. Including expert facilitators had a positive impact on the overall acceptability of the programme. However, the inclusion of parents as co-facilitators of the COMPAS programme undoubtably also had a positive effect on the participants sense of being able to master the strategies being taught. Furthermore, PET programmes should aim to have parent' involvement in the development of training materials (video modelling) if the programme aims to bolster PSE.

Divan et al., (2015) and Rahman et al., (2016) documented similar findings in when evaluating an adapted intervention in two LMIC countries, namely in India and Pakistan. The resulting adapted intervention was evaluated in respect of its feasibility and acceptability of its delivery by non-specialist health-care workers in two low-resource settings (Divan et al., 2015). The main findings indicated that that the intervention was successfully delivered with fidelity by the non-specialist workers and produced significant improvements in parent-child communication in two of three primary outcome measures for quality of parent-child interaction. Furthermore, the intervention was found to be acceptable and relevant to the needs of the local communities, being a low-intensity intervention made it easily transferable to a LMIC setting. Additionally, the methods of delivery by non-specialist health workers was found to be feasible and acceptable. In summary, the study's findings suggest that non-specialist delivered interventions for ASD are feasible, acceptable and mostly effective in low-resource countries provided that prior careful adaptations are made to suit the local context (Divan et al., 2015; Rahman et al., 2016).

Thus, gathering stakeholder perspectives is an important step towards establishing the *acceptability* of an intervention in a particular setting (Olswang & Prelock, 2015). Researchers and therapists cannot assume that evidence-based interventions originating primarily from

HIC, will seamlessly integrate into diverse cultural contexts around the globe. Therefore, specific attention must be given to include local stakeholder perspectives and the local context in order for an intervention to succeed (Franz & Dawson, 2019). We therefore anticipate that using a multi-stakeholder participatory approach may be advantageous for future PET programme selection and evaluation in resource constrained environments. Stakeholders provided valuable feedback which shaped the development of the programme. From the results it is clear that a multiple stakeholder participation is crucial to identify efficacious content and criteria for PET programmes and parent involvement in the delivery of the programme, had numerous benefits.

### 6.2.4. Discrepancies in Performance on the Two PSE Tools

In both theoretical and empirical work parental cognitions are perceived as playing an important role in parent-child interactions. One type of parental cognition well recognised in literature is parental self-efficacy (PSE) (Coleman & Karraker, 1998). The COMPAS programme was designed to enhance PSE.

To measure reliable change in parents' sense of efficacy the study employed the use of two formal tools; the Parenting Sense of Competence (PSOC) and the Parenting Self Efficacy Measuring Instrument (PSEMI) both tools have strong theoretical and conceptual coherence. However, an unexpected finding of the study is that although both of these tools measure parental self-efficacy, only the PSEMI indicates significant change in PSE after the intervention. The training did not produce equal results. In the COMPAS study, the PSOC did not show a statistical difference in change.

In order to establish reasons for the disparity in the results between the PSOC and the PSEMI, both designed to measure parental self-efficacy, we explore each of the tools and how well aligned they are for the purpose of this study. Firstly, both tools have differences in their design and construction, the PSOC is a domain-*general* measure, while the PSEMI is a domain-*specific* measure (Gibaud-Wallston & Wandersman., 1978; Harty, 2009). The PSOC being the more widely used of the tools, is composed of two subscales, one being *efficacy* and the other one being *satisfaction*. The design of the COMPAS parent training was to improve knowledge and skills, as well as increase parent self-efficacy. This was achieved by making routine tasks, such as meal and playtimes easier for parents to facilitate interaction and communication with their child. Thus, the training programme was not designed to improve satisfaction with

parenting, but it was designed to improve parental self-efficacy. Therefore, we postulate that the *satisfaction* subscale of the domain-general measure (PSOC) distorts the results in a short-term intervention study such as this. It is unlikely that a parent's sense of satisfaction with their parenting can significantly be improved in low intensity study, after 3 brief sessions (12 hours). However, it appears from the results of the study that one can effectively work on improving parent self-efficacy/competency during this time.

An additional premise is proposed as follows; the PSEMI is a task-specific measure, focusing on six specific parenting domains (showing affection and empathy, engaging in play, facilitating routines, establishing discipline strategies, scaffolding learning and development and promoting communication interaction) and its formulation adheres very closely to Bandura's (1969) development criteria for self-efficacy (Harty, 2009). Since the training programme is designed to modify parent-self-efficacy it is logical that the design of the PSEMI would be more sensitive in measuring change in parent self-efficacy. This would seem to indicate that the task-specific measure (PSEMI) offers greater discriminatory power as it is better graded to determine current levels of PSE across parents. These results indicate that; (i) the PSEMI is a reliable and valid parent self-efficacy measuring instrument (ii) and that after 10-12 hours of training, a statistically significant change in PSE levels can be seen.

This suggests that COMPAS can be effective in improving parenting skills and feelings of competence and is a cost-effective intervention in LMIC settings. Future parent training programmes focusing on PSE may well consider employing a domain-specific tool as an outcome measure it is more sensitive to measuring change brought about by PET. Furthermore, it may be beneficial if the PSOC is being used in future studies, to present data about the efficacy subscale only, as outlined in the Hohlfeld et al. (2018) systematic review.

Lastly, although parent satisfaction was not directly addressed by the parent training programme, the researchers noted an unexpected increase in social support amongst parents within the group, a result of the rapport parents established while being trained together in a group. Additionally, group programmes have the additional benefit of encouraging mutual support and opportunities to share personal experience with other parents (Dawson-Squibb, Davids, Harrison-Johnson, et al., 2019). Consequently, future research needs to explore the effect of the social support provided in group-based PET on parents' satisfaction in their parenting role.

### 6.2.5 Not All Parents Benefitted Equally from the Training

Reliable change refers to the extent to which the change shown by a participant falls beyond the range which could be attributed to the measurement variability of the instrument itself. This measurement variability has been termed the Reliable Change (RC) Index (Evans et al., 1998). Findings of the current study show that 45% (n=14) demonstrated reliable improvement and an additional 52% made some improvement on the PICCOLO tool which measures parenting interactions. Additionally, 32% of parents (n=10) showed a reliable improvement and an additional 39% showed some improvement on the PSEMI tool which measures self-efficacy. The results of the current study are comparable to published data for other parent coaching and parent training programmes which indicate reliable change for 30%-50% of parents who enrolled in the studies (Ginn et al., 2017; Kristelle et al., 2018; Leung et al., 2013; Sofronoff et al., 2011).

The small percentage of participants who did not demonstrate improvement in self-efficacy scores were potentially parents of children who had higher language scores upon entering the programme. The PLS total language age score ranged from 6 months to 60 months, indicating that although the mean language age was 56.2 months the range in scores was substantial. In this study, the participants who made the most improvement in parent-self efficacy were the parents whose children had the lower PLS language scores at pre-test as determined in the linear regressing. This affirms that the COMPAS PET programme works well for parents of children with significant language difficulties as the strategies included are early language intervention strategies which are more appropriate for pre-verbal and minimally verbal children. Parents of children with milder language problems might benefit from a different kind of intervention. Thus, these results help clinicians by providing a rationale as to which parents are likely to benefit most from a PET programme focusing on teaching contingent responding to parents.

## 6.3. Study Strengths

The findings of this study extend the existing literature in a number of ways:

- This study contributes to the body of evidence documenting that parent education and training programmes are an effective first line intervention in LMIC (Dawson-Squibb, Davids, Harrison-Johnson, et al., 2019; Makombe et al., 2019). This is an important

strength, since there are very few non-proprietary parent education and training programmes which are acceptable and appropriate to implement in LMICs. In addition, although COMPAS was implemented in a LMIC, the clinically significant changes seen in PSE and PCI are comparable to parent education and training programmes conducted in HIC.

- This study demonstrates that parent education and training programmes are effective when administered by healthcare professionals other than psychologists. This finding is of significance specifically in resource constrained LMIC, where complete multi-disciplinary healthcare teams are scarce and not always well-established (De Vries, 2016; Hohlfeld et al., 2018).
- Another study strength is that the study overtly maps common parent and training programme teaching strategies onto modifiers of parenting self-efficacy outcomes, which is not routinely reported in the literature. This is important as it provides developers with a sense of the types of activities which should be included in a PET programmes if the goal is to increase parents' belief that they can successfully parent their child.
- Finally, this study provides evidence to suggest that a brief parent education and training programme focussing on improving positive parenting interactions is effective as there are even fewer programmes which focus on teaching skills to parents to improve their abilities to respond to their child's communication attempts, despite the high percentage of children with ASD who have significant language impairments.

### 6.4. Study Limitations

We acknowledge several limitations of this study. This included the fact that the assessors who rated parent-child interactions on the PICCOLO videos were not blinded to the study aims. We also acknowledge that due to pre-testing time constraints, the sample size in phase 3 is small (n=30). Additionally, while we sampled from a low socio-demographic population, despite our best efforts, we acknowledge that the parents who responded to the study are not representative of families from the Western Cape population.

Further limitations relate to the single group design used to collect data in phase 3; namely that it utilised non-randomised sampling; that a control group was not included and that follow up

data for PSE and PCI were not collected. Lastly, we acknowledge that our decision to include a limited range of stakeholders may receive criticism.

### 6.5. Future Research Directions

The results of the current study indicate that group-based parent education and training programmes have a significant effect on the enhancement of parent-child interaction and parent self-efficacy levels for parents of young children with autism. The study offers several directions for future research, which are listed below

- Determining the effectiveness of implementing COMPAS with parents of children with neurodevelopmental disabilities other than autism spectrum disorders.
- Evaluating COMPAS effectiveness using a more methodologically rigorous design, such as a randomised control trial (RCT) to minimise sources of bias and improve the generalizability of results.
- Documenting the effect of including home visits on parents' abilities to implement the strategies taught in COMPAS, and its effect on parent child interactions would be advantageous.
- Describing implementation facilitators and barriers identified by stakeholders from multiple settings. In addition to the current stakeholders involved in the development of the programme, researchers should also consider including funders, administrators and managers from provincial and national departments (such as Education, Social Development and Health). Gathering data about appropriateness from multi-sectorial stakeholders may increase the likelihood of the programme being funded and implemented to families and their children awaiting services.
- Conducting a cost analysis study to determine COMPAS's feasibility from a cost-effectiveness point of view.

### 6.6. Conclusion

In South Africa, there is a concern surrounding the lack of autism-specific services in the public sector. Private-sector services are more readily available but come at an exorbitant cost, which means that many parents cannot access them. As researchers within an African context we recognise the necessity to develop and evaluate parent education and training programmes

which are feasible, acceptable and appropriate in low-and middle-income countries. These programmes are a vital first line intervention for parents of young children with ASD. Due to the shortage of non-proprietary, affordable and appropriate parent education and training programmes, we designed a group-based programme to enhance parent communication-interaction for parents of young children with ASD and a significant language delay. Parents and professionals rated the programme as appropriate and acceptable. Participants demonstrated significant improvements in positive parenting interaction and parenting self-efficacy after taking part in the training. Clinical implications indicate that speech and language pathologists can design and implement successful parent education and training programmes. The findings of this study extend the increasing body of empirical evidence documenting the positive effects of parent education and training programmes on families of children with ASD living in low-and middle-income countries.

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# Appendix 1. UCT HREC Approval Letter

**UNIVERSITY OF CAPE TOWN**
**Faculty of Health Sciences**
**Human Research Ethics Committee**

**Room E52-24 Old Main Building**
**Groote Schuur Hospital**
**Observatory 7925**
**Telephone** [021] 406 6492
**Email:** sumayah.ariefdien@uct.ac.za
**Website**: www.health.uct.ac.za/fhs/research/humanethics/forms

18 May 2016

**HREC REF: 242/2016**

**Dr M Harty**
Communications Sciences & Disorders
Health & Rehab Sciences
F-45
OMB

Dear Dr Harty

**PROJECT TITLE: IMPLEMENTING A GROUP INTERVENTION PROGRAMME WITH PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER (MSc-candidate-A Osman)**

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee (HREC) for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

**Approval is granted for one year until the 30 May 2017.**

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

**Please quote the HREC REF in all your correspondence.**

***We acknowledge that the student, Aneesa Osman will also be involved in this study.***

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval before the research may occur.

Yours sincerely

Signature removed

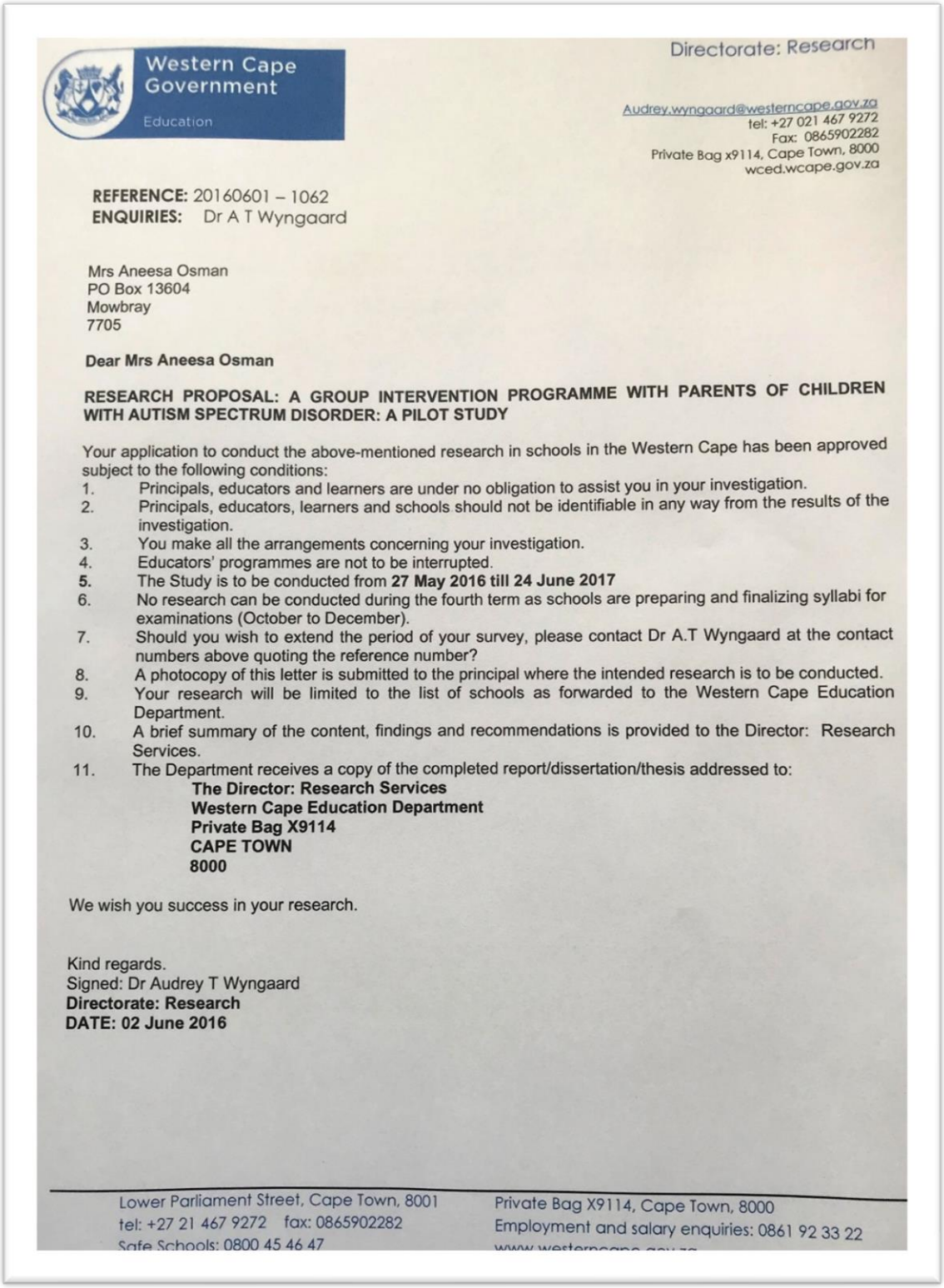
**PROFESSOR M BLOCKMAN**
**CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE**

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

HREC 242/2016

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI),and Declaration of Helsinki (2013) guidelines.
The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

# Appendix 2. WCED Ethics Approval Letter



Western Cape Government
Education

Directorate: Research

Audrey.wyngaard@westerncape.gov.za
tel: +27 021 467 9272
Fax: 0865902282
Private Bag x9114, Cape Town, 8000
wced.wcape.gov.za

**REFERENCE:** 20160601 – 1062
**ENQUIRIES:** Dr A T Wyngaard

Mrs Aneesa Osman
PO Box 13604
Mowbray
7705

**Dear Mrs Aneesa Osman**

**RESEARCH PROPOSAL: A GROUP INTERVENTION PROGRAMME WITH PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER: A PILOT STUDY**

Your application to conduct the above-mentioned research in schools in the Western Cape has been approved subject to the following conditions:

1. Principals, educators and learners are under no obligation to assist you in your investigation.
2. Principals, educators, learners and schools should not be identifiable in any way from the results of the investigation.
3. You make all the arrangements concerning your investigation.
4. Educators' programmes are not to be interrupted.
5. The Study is to be conducted from **27 May 2016 till 24 June 2017**
6. No research can be conducted during the fourth term as schools are preparing and finalizing syllabi for examinations (October to December).
7. Should you wish to extend the period of your survey, please contact Dr A.T Wyngaard at the contact numbers above quoting the reference number?
8. A photocopy of this letter is submitted to the principal where the intended research is to be conducted.
9. Your research will be limited to the list of schools as forwarded to the Western Cape Education Department.
10. A brief summary of the content, findings and recommendations is provided to the Director: Research Services.
11. The Department receives a copy of the completed report/dissertation/thesis addressed to:

    **The Director: Research Services**
    **Western Cape Education Department**
    **Private Bag X9114**
    **CAPE TOWN**
    **8000**

We wish you success in your research.

Kind regards.
Signed: Dr Audrey T Wyngaard
**Directorate: Research**
**DATE: 02 June 2016**

# Appendix 3. Information and Consent Letter for Parents

**UNIVERSITY OF CAPE TOWN**

**Faculty of Health Sciences**

**Department of Health and Rehabilitation Sciences**

Divisions of Communication Sciences and Disorders,

Nursing and Midwifery, Occupational Therapy, Physiotherapy

F45 Old Main Building, Groote Schuur Hospital,

Observatory 7925

Tel: +27 (0) 21 406 7667

Fax: +27 (0) 21 406 6323

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Information Letter and Consent Form

June 2016

Dear Parent

**Implementing a group intervention programme with parents of children with Autism Spectrum Disorder (age 2-7years and 11 months): Effects on parent interactions and parent self-efficacy. (HREC number:242/2016)**

I am currently completing my Master's Degree in Speech-Language Pathology through the University of Cape Town. In order to complete the requirements of my course, I need to conduct a research study. Ethics approval from the University of Cape Town's Faculty of Health Sciences Human Research Ethics committee has been obtained (242/2016) for me to do this.

I have chosen to conduct my research in the field of Autism Spectrum Disorder (ASD), more specifically at providing a 10-12 hour group parent education and training programme for parents of children between the ages of 2.0-7.11 years and who are presently on the Western Cape ASD Centralised Waiting List. My study will look at investigating how effective a group parent training programme is in improving parents' abilities to stimulate and develop communication and language skills in young children with autism. I am also interested in looking at how the programme affects your confidence as a parent.

There are many children on the Western Cape's waiting list for children with autism who have no or limited access to speech therapy services. Research shows that the sooner children with ASD receive intervention the better their chances for future success. As a parent, you are your child's first and best teacher of language and play an important role in supporting and raising your child.

If you agree to participate in this study, you will greatly assist me in determining how valuable this programme is in supporting other parents like yourself, in better encouraging communication and interaction between you and your young child.

Your participation is completely voluntary (of your own will) and there are no consequences if you choose not to participate. Your child's name on the waiting list for placement at a school, will not be affected by whether you choose to participate in this training programme or not. An amount of R25 will be given to you at the end of every session to use towards transport. This programme will be held once a week on a Saturday morning between 08h30 -11h30 in a training venue at Groote Schuur Hospital. Three consecutive Saturday morning sessions will be held. During the course of the training we will request that the same parent who begins the training, attends every session so that one parent receives input on the full training model.

Children are not required to attend the training programme which is only for parents. The only time we will require you to bring your child along is when we will take a video recording of you interacting with your child before the training begins and after the training ends. We would also like to document the way your child communicates at the moment. We will do this by performing a language test with your child. This testing will only happen once. We will do this on the same day we video record you and your child. The recordings we take of you playing with your child will be stored in a secure place and won't be available to anyone other than the researchers. The recordings will also be deleted once the study is completed.

During the training programme, you do not have to share any information you are not comfortable with. At any point in the study you may choose not to answer certain questions or take back consent for certain or all information you provided to be used in the study. If you do choose to participate the information you share with us will not be traceable to you in any manner. All documentation with your name or the name of your child and all personal details will be kept strictly confidential. None of the personal information you give us will be shared with anyone else. All information collected by the researcher is confidential and will only be used for the research study. The researcher however, cannot ensure that information discussed amongst other group members will remain confidential.

There are no known risks involved in the participation of this study. The results of the study will show whether parents' beliefs are related to successful parenting and whether providing support in the form of parent education and training affects how parents communicate and interact with their child on a daily basis. We will provide you with a summary of the results at the end of the study. In addition, results may be published in a research paper or presented at a conference for professionals who provide services to children with ASD.

If you have any questions about the project, you can call me at 078 8654234 or Dr. Michal Harty at 021 406 6313. You can call Prof. Marc Blockman, Chair of the Human Research

Ethics Committee on 021 406 6492 if you have any questions regarding your rights or well-being as participants in the study. Thank you sincerely, for considering this invitation to participate in our study.

**Primary Researcher and Speech-Language Pathologist: Aneesa Osman**

**Email**: aneesa.osman@gmail.com **Contact Number**: 078 8654234

**Research Supervisor: Dr. Michal Harty (Snr Lecturer, Communication Sciences & Disorders, UCT)**

**Faculty of Health Sciences, University of Cape Town**

**Email:** michal.harty@uct.ac.za **Contact Number:** 021 4066313

**Prof. Marc Blockman**

**Chair of Human Research Ethics Committee, University of Cape Town**

**Email:** marc.blockman@uct.ac.za **Contact Number:** 021 406 6492

**Informed consent to participate:**

I have been invited to participate in the UCT Master's study. The information has been read by me or to me and I understand the risks, benefits and my role in participation. I have had the opportunity to ask any questions about the study and they have been answered to my satisfaction.

---

I **give** my voluntary consent to participate in the study. ☐

I **do not give** my consent to participate in the study. ☐

---

I **give** my voluntary consent to a video recording of my interaction with my child. ☐

I **do not give** my consent to a video recording of my interaction with my child. ☐

---

I **give** my voluntary consent to have my child's communication assessed. ☐

I **do not give** my consent to have my child's communication assessed. ☐

_____

*If participant cannot read for any reason:*

I have witnessed the correct reading of the consent form to the participant; they have had opportunity to ask any questions about the study and have full understanding. I confirm that they have given consent voluntarily.

Name of witness _____ Thumb print of participant

Signature of witness _____

Date _____

# Appendix 4. Overview of Training Programme

## Overview of Training Programme:

## Training strategies and rationale for inclusion

| Session | Strategy | Rationale |
|---|---|---|
| 1 | *Theory on Autism Spectrum Disorder (ASD).*<br>*What is Language Stimulation Teaching and Why learn language stimulation strategies?* | Explaining basic theory on the areas of impairment related to ASD and how they may act as barriers to language and communication development will be beneficial in creating an understanding of how language stimulation can be used during everyday situations to develop and expand language skills in children (Kaiser & Gray, 1993) |
| | *Environmental Arrangement* | The purpose of *Environmental Arrangement* is to create a setting for both teaching and learning language. This is achieved by selecting activities and materials that are of interest to the child. Many children with ASD have restricted patterns of interest. Therefore, having materials available that are of interest to the child will support and encourage the child to engage with the materials and increases opportunity for interaction with the adults (Hancock & Kaiser, 2006) |
| 2 | *Responsive Interaction* | Children with ASD present with limited communicative intent due to an impaired need to interact socially (Boyd et al., 2010). The strategy behind *Responsive Interaction* is to engage the child in non-verbal and verbal interactions to provide a variety of opportunities for modelling new language |

| | | |
|---|---|---|
| | | forms, thereby increasing the likelihood that the child will interact with the adult (Hancock & Kaiser, 2006).<br>Joint attention is a crucial social-communicative skill where an adult and child share attention in respect of one common object or activity (Kaiser & Gray, 1993). Joint attention is developed incidentally in neurotypical children, but often limited in children with ASD. *Facilitation of Joint Attention* will be addressed through the technique of 'mirroring' and 'mapping', where the adult joins the child in his/her activity and takes turns doing the same action the child is doing (Kaiser & Hancock, 2003) |
| | *Modelling and Expanding Language* | Many children with autism have limited functional vocabularies, or use vocabulary that is only limited to their interests. Language modelling provides children with specific models of targeted language forms, by modelling the child's previous communication and adding a new word (*expansion*) (Hancock & Kaiser, 2006) |
| 3 | *Milieu Teaching Strategies (also known as incidental teaching or, creative temptations)* | This is a strategy that is used where opportunities are created in the environment to allow for initiation and spontaneous communication. This strategy allows the child to progress from imitating to independently initiating communicative acts (Hancock & Kaiser, 2006). |
| | *Question and Answer Session and Conclusion of Intervention Programme* | An informal, interactive question and answer session regarding training content and related topics will be afforded to parents. Particularly |

| | | |
|---|---|---|
| | | to problem solve and discuss any issues that may have arisen prior to the follow up session. Opportunity for parent feedback and reflection will be allowed for. The training programme will then be concluded. |

# Appendix 5. Sample Session of Training Programme

**UNIVERSITY OF CAPE TOWN**

**Faculty of Health Sciences**

**Department of Health and Rehabilitation Sciences**

Divisions of Communication Sciences and Disorders,

Nursing and Midwifery, Occupational Therapy, Physiotherapy

F45 Old Main Building, Groote Schuur Hospital,

Observatory 7925

Tel: +27 (0) 21 406 7667

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***Sample Session of Group Parent Training Programme: COMPAS***

Session:2 Duration of Session: 3hours

- 08:30 – 08:45: Welcome and Recap of previous session (15 minutes)
- 8:45 – 9:30: Introduction of new skill (e.g. *Responsive Interaction*) (45 minutes)
- 9:30 – 9:45: Video demonstration of how to implement new skill and discussion (15 minutes)
- 9:45 – 10:00: Demonstration of skill with expert parent and child with autism (15 minutes)
- 10:00 – 10:30: Participants divide into small groups and practice skill with facilitator (role play) (30 minutes)
- 10:30 – 11:00: Participants divide into small groups and discuss how to implement skill in selected routine at home (30 minutes)
- 11:00 – 11:15: Tea and Coffee Break (15 minutes)
- 11:15 – 11:25: Problem Solving: "What do I do if…?" (10 minutes)
- 11:25 – 11:30: Wrap up and Conclusion of session (5 minutes)

# Appendix 6. Professional Appropriateness Evaluation Tool (PAET: Professional)

**Professional appropriateness evaluation tool (PAET: professional)**

Implementing a group intervention programme with parents of children with Autism Spectrum Disorder: Effects on parent interactions and self-efficacy (HREC No.: 242/2016)

Dear Expert:

We value your feedback on the following four elements of the group parent training programme.

Aim of project: The study will investigate the effectiveness of a group parent training programme in children with autism. The intervention programme will be delivered on a Saturday. Each parent will receive 10 hours of training over one full day. This pilot study hopes to demonstrate that group-based parent and education training programmes focussing on early language stimulation results in significant improvements in parent's abilities to facilitate communication interaction in young children with ASD; as well as demonstrating improvement in parent's self-efficacy levels.

Target Audience: This study will include 60 parents. Each parent must have a child on the Western Cape Education Department's Consolidated Waiting List for ASD. The children must be between 2 and 7.11 years of age, have a confirmed diagnosis of ASD and receive 4 hours or less of monthly therapeutic intervention.

Materials included for review:

a) Training Manual
b) Power point presentation
c) Expert parent videos
d) Agreement and consent form for experts to sign and return

Please place an X in the box that best corresponds to how you feel about each question (A-D).

| | 1<br>Not relevant/ comprehensive | 2<br>Needs revision | 3<br>Relevant/ comprehensive but needs minor alterations | 4<br>Very relevant/ comprehensive |
|---|---|---|---|---|
| A. **Relevance** of **content** (ASD introduction and 4 communication strategies) | | | | |
| B. **Comprehensiveness** of **content** (ASD introduction and 4 communication strategies) | | | | |
| C. **Relevance** of training activities (group training, small group discussions, expert parent panel discussion) | | | | |
| D. **Relevance** of teaching materials (manual, video modelling, power point presentation) | | | | |

We value your input and realise that you might like to provide us with some additional comments about the training programme. Please complete the section below if you have anything else you would like to add. If you don't want to add anything, please answer "not applicable" to each question.

A. If you have anything else to share with us about the relevance of the content please let us know here:

B. If you have anything else to share with us about the comprehensiveness of the content please let us know here:

C. If you have anything else to share with us about the teaching tools/delivery methods please let us know here:

D. If you have anything else to share with us about the delivery (training) methods please let us know here:

Please feel free to share any other thoughts or comments with us here:

We thank you for your time and valuable contribution towards our parent training programme.

Kindly return this form back to me.

Aneesa Osman: 0788654234 (aneesa.osman@gmail.com)

Dr Michal Harty (supervisor): 021 4066313 (michal.harty@uct.ac.za)

# Appendix 7. Parent Acceptability Evaluation Tool:

# (PAET: Parent)

**Parent acceptability evaluation tool: (PAET: parent)**

Response choices for the items in this scale ranges from 1 (strongly disagree) to 6 (strongly agree)

**Perception about the acceptability of the *goals* of the training programme:**

**1) I believe my child's communication is a high priority.**

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| Strongly Disagree | Somewhat Disagree | Disagree | Somewhat Agree | Agree | Strongly Agree |

**2) I believe I have a role to play in teaching my child to communicate.**

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| Strongly Disagree | Somewhat Disagree | Disagree | Somewhat Agree | Agree | Strongly Agree |

**3) I want my child to be able to tell me things that interest him.**

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| Strongly Disagree | Somewhat Disagree | Disagree | Somewhat Agree | Agree | Strongly Agree |

**4) I want my child to initiate communication with me more often.**

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| Strongly Disagree | Somewhat Disagree | Disagree | Somewhat Agree | Agree | Strongly Agree |

**Open ended question:**

Tell me why you decided to attend this training session?

**Perception of acceptability of training programme *content* and *procedures:***

1) **I am satisfied with what was taught during the training.**

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| Strongly Disagree | Somewhat Disagree | Disagree | Somewhat Agree | Agree | Strongly Agree |

2) **I am satisfied with the way in which the training was structured.**

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| Strongly Disagree | Somewhat Disagree | Disagree | Somewhat Agree | Agree | Strongly Agree |

3) **I enjoyed being able to talk with other parents who have children with ASD at the training.**

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| Strongly Disagree | Somewhat Disagree | Disagree | Somewhat Agree | Agree | Strongly Agree |

4) **I understand the strategies that were taught during the training.**

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| Strongly Disagree | Somewhat Disagree | Disagree | Somewhat Agree | Agree | Strongly Agree |

**Open ended question:**

Tell me what you enjoyed learning about the most today?

Is there anything else we should include in our programme?

**Parent perception of acceptability of communication *outcomes:***

**1.) I think I will enjoy using these new strategies with my child.**

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| Strongly Disagree | Somewhat Disagree | Disagree | Somewhat Agree | Agree | Strongly Agree |

**2.) These new strategies will improve the way my child and I communicate with each other.**

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| Strongly Disagree | Somewhat Disagree | Disagree | Somewhat Agree | Agree | Strongly Agree |

**3) I believe this training will help me to understand my child better.**

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| Strongly Disagree | Somewhat Disagree | Disagree | Somewhat Agree | Agree | Strongly Agree |

**4) I would recommend this training to a friend who was concerned about his/her child's communication skills.**

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| Strongly Disagree | Somewhat Disagree | Disagree | Somewhat Agree | Agree | Strongly Agree |

**Parent perception of competence *outcomes:***

**1) I can teach language to my child while we play.**

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| Strongly Disagree | Somewhat Disagree | Disagree | Somewhat Agree | Agree | Strongly Agree |

**2) I can teach language to my child during everyday routines.**

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| Strongly Disagree | Somewhat Disagree | Disagree | Somewhat Agree | Agree | Strongly Agree |

**3) I am confident that I can use these strategies with my child.**

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| Strongly Disagree | Somewhat Disagree | Disagree | Somewhat Agree | Agree | Strongly Agree |

**4) I think I can teach other family members what I learnt at the training.**

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| Strongly Disagree | Somewhat Disagree | Disagree | Somewhat Agree | Agree | Strongly Agree |

**5) I am confident that I can use at least 1 of the new strategies at home with my child.**

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| Strongly Disagree | Somewhat Disagree | Disagree | Somewhat Agree | Agree | Strongly Agree |

**6) I think that I can now support my child so he can learn new words and phrases.**

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| Strongly Disagree | Somewhat Disagree | Disagree | Somewhat Agree | Agree | Strongly Agree |

**Open ended question:**

Tell me one new strategy today that you will try to do at home with your child?

What challenges do you forsee to trying to do these strategies at home with your child?

***Is there anything else that you would like to share with us?***

# Appendix 8. Demographic Questionnaire

**Dear Parent, please answer all questions below, all information is confidential.**

1. How old are you? _____
2. Are you a male or female? _____
3. Which cultural group do you belong to (e.g. White, Indian, etc.)?

   _____
4. What language/s do you speak at home?

   _____
5. How many adults are there in your home? _____
6. Is there anyone in your family who helps with caregiving, if so who?

   _____
7. Are you employed? If so, please state if you are employed *full time* or *part time*?

   _____
8. What is your highest level of education? _____
9. How many children do you have? _____
10. How old is your child with autism? _____
11. At what age (or in which year) was your child diagnosed with ASD?

    _____
12. Do you have any other children with special needs requirements?

    _____

13. If you have other children who have special needs, please list what disorder/s they have been diagnosed with or what difficulties they present with:

    _____

14. Do you own your own home? _____
15. Do you own your own car? _____
16. Do you have access to email? _____
17. Does your child with ASD receive any therapeutic interventions? If so, please list them and how frequently he/she attends these therapies/interventions

    _____

    _____

18. Approximately how much do you spend per month on ASD services and therapeutic interventions?

    _____

19. Is your child who has ASD placed at an educational setting? If so, where and is it a permanent placement?

    _____

Thank you for your time and valuable input.

# Appendix 9. Toy Set and Associated Vocabulary List

## VOCABULARY IDEAS FOR FRUIT COOKING SET

| ***Nouns*** | ***Verbs*** | ***Prepositions*** | ***Adjectives*** | ***Phrases*** | ***Request Words*** |
|---|---|---|---|---|---|
| Pear | Cut | In | Red | Put in | Finished |
| Pineapple | Chop | On | Yellow | Cut tomato | More |
| Tomato | Slice | Out | Green | Red tomato | Again |
| Orange | Put | Off | Blue | Take off | My turn |
| Lemon | Give | | Purple | Take out | Your turn |
| Kiwi | Want | | Brown | Big pot | Wait |
| Apple | Stir | | Pink | Little pot | Stop |
| Strawberry | Eat | | Big | More cut | Look |
| Grapes | Blow | | Little | More Stir | Pack away |
| Plum | | | Hot | Eat fruit | |
| Spoon | | | | Puppet eat | |
| Knife | | | | Stop cutting | |
| Plate | | | | Give me | |
| Pot | | | | On plate | |
| Pan | | | | Want spoon | |
| Cutting board | | | | Want knife | |
| Puppet/doll | | | | In pan | |
| Salt | | | | In pot | |
| Pepper | | | | On plate | |
| Stove | | | | On board | |
| | | | | Finished cut | |
| ***Pronouns*** | ***State Verbs*** | ***Negatives*** | | Finished stir | |
| Me | Hungry | No | | Finished eat | |
| You | | Don’t | | | |
| I | | | | | |

# Appendix 10. Procedural Integrity Checklist

**UNIVERSITY OF CAPE TOWN**

**Faculty of Health Sciences**

**Department of Health and Rehabilitation Sciences**

Divisions of Communication Sciences and Disorders,

Nursing and Midwifery, Occupational Therapy, Physiotherapy

F45 Old Main Building, Groote Schuur Hospital,

Observatory 7925

Tel: +27 (0) 21 406 7667

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## ***Procedural Integrity Checklist of Sessions*: COMPAS Programme**

Date: _____ Session Number: _____

1. Greets and welcomes participants
2. Explains the outcome of the session and introduce new skill
3. Introduces expert parent
4. Facilitates parent demonstration of skill
5. Facilitates group discussion during role play activity
6. Facilitates group discussion on home implementation
7. Allows parents a chance to ask questions and leads problem-solving discussion
8. Concludes session

Completed By: _____ (name)